Coventry University

MASTER OF SCIENCE BY RESEARCH

Clinical Practice: A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire

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Award date:
2017

Awarding institution:
Coventry University

Link to publication

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Clinical Practice: A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire

By

Zoe L Connor

May 2017

A thesis submitted in partial fulfilment of the University's requirements for the Degree of Master of Science by Research

Certificate of Ethical Approval

Applicant:

Zoe Connor

Project Title:

A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

18 March 2016

Project Reference Number:

P38615

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Acknowledgements

Thanks to Deborah Lycett, Kathleen Hennessey-Priest and Rosie Kneafsey for their support and encouragement throughout my project as my university supervisory team.

Thanks to Sarah Cooke and Sally Brothers for their support and encouragement throughout my project and their support for my original application as my clinical team lead, clinical supervisor and manager.

Thank you to the participants and their children for their candid participation and enthusiasm for the project.

Finally thank you to the National Institute for Health Research and Health Education England for funding this research and my studies.

Abstract

Background: Autism spectrum disorder (ASD) is a complex neurodevelopmental condition affecting 1% of children. 60-90% of children with ASD experience feeding problems such as extremely fussy eating.

Aim: To examine the experiences of parents of children with ASD who have eating problems; the support they have received; and the additional support they would like.

Methods: A pragmatic qualitative research approach with an element of participatory photography was adopted. Six participants were recruited using purposive and snowball sampling. All were mothers in their 40s who lived in Lewisham. Data was collected via semi-structured interviews and all participants additionally submitted photographs with captions that illustrated their child's eating problems and the effect on them and their family. Interviews were transcribed, and the transcripts, photos and captions analysed using inductive thematic analysis. Rigour was ensured via member checking, peer review of themes and reflexive journaling.

Results: Themes showed that parents and children found 'mealtimes difficult' and they were 'unsure when or whether to pursue help'. Parents reported 'lowered expectations of parents and professionals' regarding their child's eating problems, and 'the challenge of finding support'. Parents expressed their desire for 'services that are easily accessible and supportive'.

Discussion: This research has provided the first UK exploration of parental experience of feeding problems in children with ASD. It supports findings from studies in North America and Australia that these problems have a negative impact on the child, parent and family wellbeing. It has been the first study to explore the services used and desired in the NHS.

Conclusion: In-depth exploration of the experiences of six parents of children with ASD and feeding problems has been carried out. The study findings will be used to better plan services with the overriding aim of improving the wellbeing of children with ASD their families in Lewisham.

1.0 Introduction

1.1 Autism spectrum disorder

Autism spectrum disorder (ASD) is a childhood condition affecting at least 1% of children in the UK (National Institute for Health and Care Excellence (NICE), 2011). ASD is "a condition that affects social interaction, communication, interests and behaviour" (NHS Choices, 2015). ASD diagnosis involves behavioural assessments by trained professionals such as psychologists. The American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) sets out the diagnostic criteria for ASD. This 2013 edition supersedes previous diagnoses of autism, pervasive developmental disorder not otherwise specified (PDDNOS), and Aspergers syndrome, incorporating all under one diagnostic label, ASD (Schendel et al. 2016).

ASD is a complex and varied condition ranging from individuals with few functional communication skills and severe learning disabilities, to highly intelligent individuals who thrive independently in work and personal life. Individuals with ASD have an increased risk of many conditions including anxiety, epilepsy, learning disability, nutrition deficiencies, and nutrition-related disorders such as dyslipidaemia, hypertension, diabetes and obesity (Croen et al. 2015). They also die on average 18 years younger than the general population (Hirvikoski et al. 2016). The estimated direct and indirect economic effect of ASD from medical care, special education services, parental and individual productivity loss, and residential care are £32 billion a year in the UK, double that of diabetes (Buescher et al. 2014, Diabetes UK 2014, Iemmi et al. 2017). The government has highlighted the need to reduce the health gap between people with ASD and the general population and increase UK research spend from the current £4 million per year, £6 per year per person with ASD, compared to £220 spent per person with cancer (Department of Health 2017, 2016, The Lancet Neurology 2017).

Parents of children with ASD consistently show higher levels of anxiety than parents of children without disabilities or with different disabilities (Allik et al.

2006,Bouma and Schweitzer 1990, Dabrowska and Pisula 2010, Hastings et al. 2005, Larson 2006, Olsson and Hwang 2001, Pisula 2007). Questionnaire research of 108 parents of children with ASD in Australia found more than 80% of parents reported they feel "stressed beyond their limits" (Bitsika et al. 2013). Poorer health, particularly mental health, has consistently been documented in the mothers of children with ASD (Rizk et al. 2011), Sawyer et al. 2010, Watt and Wagner 2013). A retrospective cohort study of all mothers of live-born children in Western Australia from 1983-2005 (n=300,123) showed that mothers of children with ASD were 50% more likely than mothers with a child without ASD or other disability to have died during this time, with the three main causes of death being cancer, cardiovascular disease and misadventure, with the underlying reason hypothesised to be stress (Fairthorne et al. 2014).

1.2 Eating problems associated with ASD

Typically developing children commonly experience eating problems especially in the first years of life, transient and typically benign fussy eating affects 30% of young children (Emond et al. 2010, Lewinsohn et al. 2005). More severe eating problems in children impact on health, behaviour and parental stress (Crist and Napier-Phillips 2001, Dovey et al. 2013, Nicholls and Bryant-Waugh 2009).

The typical characteristics of ASD: rigid thinking, resistance to change and sensory processing issues seem to predispose to eating problems. A comparison of dietary and feeding data from 79 children with ASD versus 12,901 controls in the Avon Longitudinal Study of Parents and Children (ALSPAC) found that eating problems are two to three times more common than in typically developing children, affecting 60-90% of children with ASD (Emond, et al., 2010). Eating and mealtime problems are different and more severe in children with ASD compared from typically developing controls with common difficulties including staying seated, not eating with their families, 'food jags' (persistently wanting the same foods), narrower food repertoires, restrictions by food category, texture, and the way they are presented (Johnson et al. 2008, Ledford and Gast 2006, Nadon et al. 2011, Schreck et al. 2004).

There is a lack of consensus for eating problem terminology and definitions. The terms selective eating, restricted eating and perseverant eating are often used to describe dietary intakes that are poorly varied and eating behaviours that are highly resistant to change. DSM-5 (American Psychiatric Association 2013) introduced the diagnosis of Avoidant Restrictive Food Intake Disorder (ARFID) which is increasingly being used to encompass these previous terms however the diagnostic criteria is subjective and diagnostic tools have yet to be developed (American Psychiatric Association 2013, Norris et al. 2016).

1.3 Impact of eating problems in ASD

Feeding problems can lead to diets that are restricted to few foods, and leave children at risk of nutrient deficiencies and faltering growth. Indeed, there have been many published cases of poor dietary intakes in children with ASD having severe life changing and life-threatening consequences. See appendix 1 for a draft copy of the author's systematic review of published case reports of severe nutrient deficiencies in children with ASD, due to be submitted for publication; 37 cases were identified 20 of vitamin C deficiency (scurvy) of which 11 presented with limb pain and walking difficulties and 2 presented with pulmonary hypertension (Berube et al. 2013, Cole et al. 2011, Dey et al. 2012, Duggan et al. 2007, Gongidi et al. 2013, Estienne et al. 2011, Retz et al. 2010, Ma et al. 2016, Monks et al. 2002, Niwa et al. 2012, Noble et al. 2007, Sobotka et al. 2014); 7 cases were of vitamin A deficiency all of which presented as visual difficulties and were only partially reversible with supplementation; and there were 10 other cases of various severe deficiencies including of magnesium, vitamin B12, iron, zinc and multiple nutrients. The vast majority - 35 of the 37 cases were due to the extreme food selectivity that is common in ASD and a number involved admission to intensive care. In an observational case-control study of 22 children with autism and 'selective eating' in the US, using a validated food frequency questionnaire, children were found to be significantly more likely than typical controls to be at risk of at least one serious nutrient deficiency (Zimmer, et al., 2012). It is not clear the extent of nutrient deficiencies in children with ASD in the UK, although the author comes across them regularly in clinical practice as a dietitian.

Additionally studies that are mainly of low quality and involving small sample sizes have raised concerns regarding differing biochemical markers of nutrition in children with ASD, including low serum iron (Hergüner et al. 2012), magnesium (Strambi et al. 2006), calcium and vitamin D (Meguid et al. 2015); increased plasma vitamin B6 (Adams et al. 2011); and various other markers (further reviewed in the author's chapter in Clinical Paediatric Dietetics (Connor 2014)). More research is needed to clarify the clinical relevance of these findings.

1.4 Management of eating problems in ASD

Evidence for the optimum treatment of eating problems in ASD is limited. The small number of published studies which show positive improvements in food volume and variety generally involve small numbers of participants and intensive multidisciplinary treatment as an inpatient in the US (something that is not available in the UK) (Marshall et al. 2015a, 2015b).

Treatment approaches for feeding problems in ASD tend to be individualised and carried out by individual therapists or multi-disciplinary teams working either directly with the child or through the parent. A survey of allied health professionals in Australia showed a wide range of approaches and frequencies of support used, and a lack of confidence in treating these complex difficulties. The most commonly used approach reported was systematic desensitisation (n=80, 83%), which involves gradual exposure to an anxiety provoking food, while using relaxation activities. Parent education approaches were used by 72 participants (75%), and visual schedules (learning supports such as pictorial step-by-step instructions to an activity) used by 71% (68 participants) (Marshall et al. 2013). This has not been studied in the UK.

Dietitians are the only health professionals trained to assess dietary adequacy and advise on diet and nutrition to improve health. Their key role in effective interdisciplinary treatment of feeding problems has been discussed in two papers. In the first, an invited review by a US paediatric psychologist, the dietitians role is highlighted as "to assess the child's nutrition status via assessment of growth, assessment of nutrient intake and identification of

nutrition concerns" and then to "provide targeted nutrition interventions" with ongoing follow up and support. (Silverman 2010). In a retrospective chart review of 104 subjects attending an interdisciplinary clinic in Canada, success rates characterised by percentage goals achieved were over 75% and the dietitians role was highlighted as the "assessment of, monitoring of, and intervention in clinical nutrition concerns with respect to growth and feeding." (Williams et al. 2006). These papers somewhat overlook the skills of dietitians in behaviour change, motivational techniques and counselling approaches that are key in facilitating dietary and feeding changes (Gable 2008).

In a UK survey of 497 people with ASD, 74% of respondents, parents of children with ASD, and professionals felt that people with ASD receive 'worse' or 'much worse' healthcare than people without ASD (The Westminster Commission on Autism 2016). A recent UK survey of 304 GPs revealed limited confidence in their abilities to manage autistic patients, and perceived failings of the current healthcare system (Unigwe et al. 2017).

A survey of 264 parents of children with ASD carried out via the parent-support charity Treating Autism found that parents reported general dissatisfaction with the majority of NHS-offered services but the lowest satisfaction rates were related to feeding problems; 24% of respondents (n=49) had been unsuccessful in getting support for diet and nutrition via the NHS, and of those who did get support 77% (n=83) did not find it helpful (Wills and Evans 2016).

1.5 Management of eating problems in ASD in Lewisham

This research was carried out in Lewisham, where the author is employed in the NHS as a paediatric dietitian. Lewisham is a borough in South East London of approximately 275,900 people, of which almost a quarter are 19 years and under; Lewisham's ASD prevalence is 2.21% (1 in 45 children), the highest in all school districts in England, totalling approximately 1525 children and young people with ASD (Public Health England, 2015)

In Lewisham, many services provide support families of children with ASD and eating problems: health visitors, speech and language therapists, occupational therapists, paediatricians, portage, physiotherapists and school staff.

Current dietetic provision for all children with special educational needs and disabilities in Lewisham who are orally fed is 0.1 full time equivalent. This provision historically provides one monthly dietetic clinic which receives referrals from GPs and paediatricians as per referral criteria, and a monthly multi-disciplinary feeding clinic. The provision of paediatric dietetic services for children with special educational needs and disabilities in neighbouring boroughs is ten times higher, with at least one full time equivalent dietitians, albeit often spread across general paediatric posts.

A report from Lewisham's public health team highlighted in 2012 that "dietetics provision within Lewisham has remained almost unchanged over the last 15 years despite an evolving evidence base demonstrating the benefits of dietetic assessment and support for children with disabilities and special educational needs … the monthly clinic is over-subscribed and faces protracted waiting lists" and recommended the creating of a community dietitian post to address and improve the health of children with complex medical and developmental special needs (Lewisham Public Health Team 2012).

An audit of the dietetic service for children with special educational needs and disabilities carried out by the author in 2015 revealed that children with or awaiting diagnosis of ASD make up the majority of new referrals (71%), and that the service was highly oversubscribed with a 33 month wait for a new appointment (Connor 2015). Subsequently the service was redesigned to provide a targeted and limited service to those at most need, however the limitations of the redesigned service in not providing adequate follow-up has been raised by the author and her team as a clinical, financial and reputational risk on the NHS trust risk register. In a service evaluation of the redesigned clinic, a key positive outcome identified by 100% of parents questioned by semi-structured phone interviews (n=10) was reassurance and relief of stress

regarding feeding, however all parents were dissatisfied with the lack of follow-up offered (Connor 2017).

1.6 Aim of this research

This research aimed to: examine the experiences of parents/guardians of children with ASD in Lewisham who have eating problems; the support they have received; and the additional support they would like.

Studying this will help to better plan services and multi-disciplinary support for the future with the overriding aim of improving the wellbeing of children with ASD their families in Lewisham and closing the gap between need and provision that has been highlighted in the introduction.

2.0 Literature review

This section reviews published literature exploring parental experiences of eating problems in children with ASD using a systematic search strategy and quality appraisal. Although a fully systematic review is out of the scope of this piece of work, a qualitative review was carried out in line with best practice set out in the ENTREQ criteria (enhancing transparency in reporting the synthesis of qualitative research) (Tong et al. 2012).

2.1 Search strategy

The literature review aims to explore the question: What are the experiences of parents of children with ASD of mealtimes and eating?

The search was carried out via EBSCOhost of the following databases: CINAHL Complete, Academic Search Complete, AMED (The Allied and Complementary Medicine Database), MEDLINE, PsycARTICLES and PsycINFO, and repeated on Scopus and PubMed.

Keyword search terms used were:

> *(autism or asd or autism spectrum disorder or asperger's or asperger's syndrome or autistic disorder or aspergers) AND (eating or feeding or mealtime) AND (qualitative research) NOT (anorexia or bulimia)*

The search included 'related words'.

Inclusion and exclusion criteria is detailed in table 1 below.

Table 1: Inclusion and exclusion criteria for literature search

Inclusion criteria	Exclusion criteria
Publications in English	Publications not in English
Qualitative studies	Quantitative studies Reviews

	Opinion pieces
Participants are parents of children and young people with ASD	
Any date of publication	

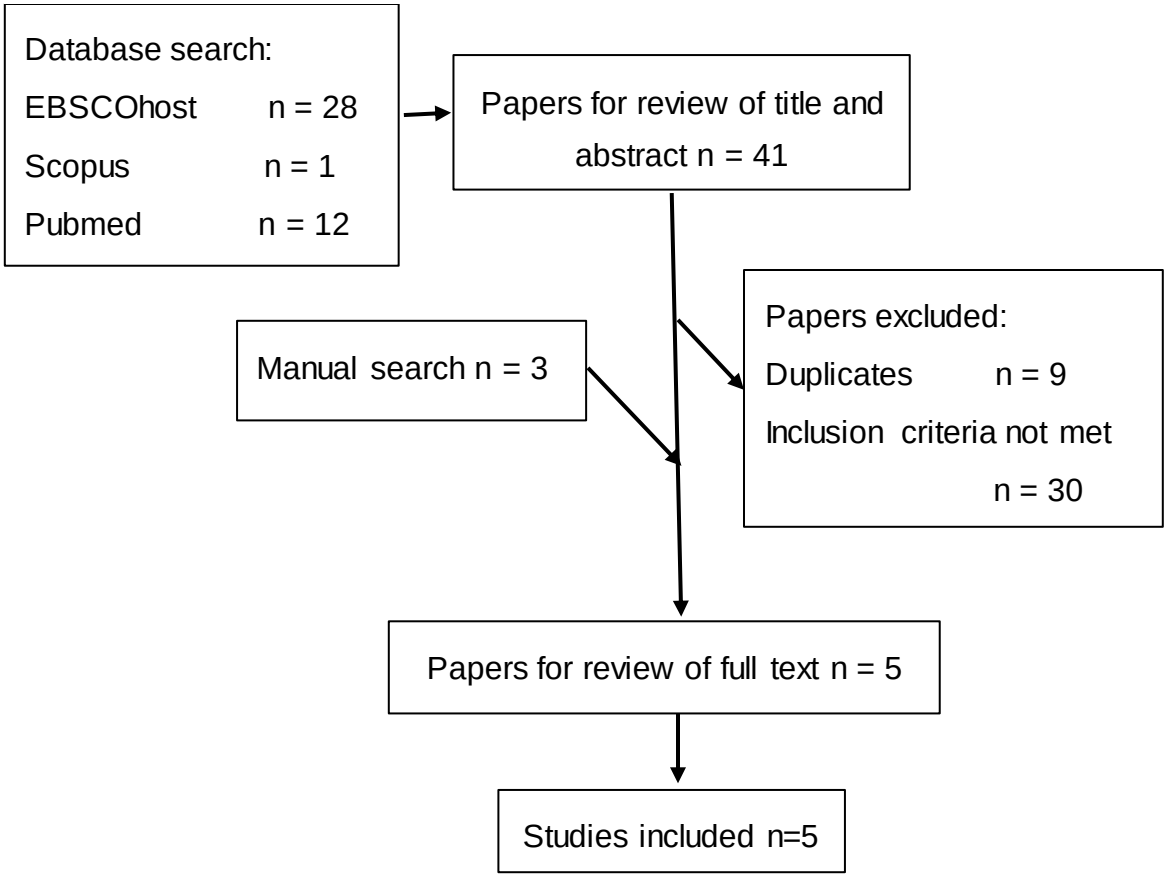
Table 2 below shows the number of papers identified. Titles and abstracts were screened for eligibility and as shown only two eligible papers were identified.

Table 2: Papers identified in literature search

Database	**Identified papers**	**Eligible papers**	**Papers included**
EBSCOhost	28	2	(Marquenie et al. 2011) (Suarez et al. 2014)
Scopus	1	0	
Pubmed	12	2	(Marquenie et al. 2011) (Suarez et al. 2014)

An additional 3 papers relevant to the search were identified from the reference lists of the above identified papers and the author's prior knowledge (DeGrace 2004, Phelps et al. 2009, Rogers et al. 2012). A flow chart of the process of the systematic search is below in figure 1.

Figure 1: Flow chart of systematic search



2.2 Quality appraisal

The included studies were appraised using a 10-point checklist from Critical Appraisal Skills Programme (CASP (Critical Appraisal Skills Programme) 2010) (appendix 2). The CASP checklist authors advise against assigning a scoring system, however to guide inclusion and exclusion of papers based on quality a pragmatic scoring was assigned using each yes on the CASP score as one point. Although a full score would be ideal inclusion was pragmatic and a score of seven or above would have been considered for inclusion. All papers scored nine or ten out of ten: The quality of the reported research was good and none of the selected articles were excluded from analysis following quality appraisal. The papers represent authentic and credible accounts of their participants.

Characteristics of the included papers and CASP 'scores' are detailed in Table 3. The following is a critique of the methodology of the included papers, followed by a synthesis of results.

2.2.1 Study 1: (Marquenie et al. 2011)

Marquenie carried out a qualitative study of 14 mothers of children with ASD aged 2-5 years old. Data was collected via semi-structed interviews, and analysed using thematic analysis as per Patton (1990). Recruitment used purposive sampling via support groups. Detailed description of the methodology is provided including evidence of care taken to enhance rigour via member checking, independent clean recoding by a second researcher, and independent coding by a third researcher. The one omission from the account is an exploration of the researcher's positionality and how that influenced her findings.

2.2.2 Study 2: (Phelps et al. 2009)

Phelps carried out phenomenological analysis of a subset of data collected as part of a larger mixed methods investigation. Data collection was via paper questionnaires. Three open-ended questions captured perspectives on stress, enrichment, usefulness of services, and overall family functioning. Participants were recruited from a local autism society. There was a return rate of 27%, resulting in 80 participants, 97% were mothers. Their children ranged from 3 to 35 years old, with the mean age of 10.75 years old and the majority under 18. The researcher explored his positionality and influence on the research in depth and analysed the data using an established method (Colaizzi 1978), ensuring rigour by triangulation, consideration of researcher bias, journaling and peer debriefing. Data analysis was carried out with rigour, however data collection via questionnaire will lack the richness of in-depth interviews.

2.2.3 Study 3: (Rogers et al. 2012)

Rogers used semi-structured interviews to explore mothers' perspectives of the processes involved in addressing the feeding challenges of children with ASD. Participants were 11 mothers of children with ASD from 4-11 years, recruited from a clinic. Data analysis used grounded theory process and constant

comparison. It was unclear whether the data analysis was carried out solely by the first author or in conjunction with others. There lacked discussion of the positionality or experience of the researcher and its influence on the research. Limitations included a low response rate to recruitment, and the high educational level of the participating mothers, leaving uncertainties as to how representative the sample was, nonetheless, the data was rich and insightful.

2.2.4 Study 4: (DeGrace 2004)

DeGrace conducted in depth interviews of five families of children with 'severe autism' aged nine to eleven, to understand the family's experiences negotiating family life and the meanings they ascribed to them. Participants were families she had worked with clinically in the previous four years, all included two parents, were interviewed together and asked to collate their accounts. Detailed account of the methodology was included. Phenomenological data analysis was based on (Moustakas 1994), and used four outside readers and additional material to validate findings. The influence of positionality and perspectives on data collection, analysis and results was explored in depth.

2.2.5 Study 5: (Suarez et al. 2014)

Suarez carried out qualitative interviews of four mothers of children with autism to gain understanding of the mealtime experience (Suarez et al. 2014). The children included were aged four to twelve and ate less than ten foods as part of their regular diet i.e. met the author's criteria for 'food selectivity' (Suarez et al. 2014). Participants were recruited as part of a larger study regarding feeding behaviours. Semi-structured interviews over the telephone were transcribed and analysed using phenomenological analysis based on (Moustakas 1994). Analysis was conducted by two investigators and discussed to form a consensus with the additional input of a qualitative expert. The methodology followed sufficient rigour however lacks consideration of the positionality of the researchers. Despite a small sample size, the researchers felt there was evidence of saturation of data.

Table 3: Details of papers included in literature synthesis

Title	Lead author	Journal	Date	Methodology	Participants	Study aim/ purpose	CASP score out of 10
Caring for an individual with autism disorder: A qualitative analysis	Kenneth W Phelps, East Carolina University, USA	*Journal of Intellectual and Developmental Disability*	2009	Phenomenological analysis of written responses to questionnaire.	80 primary caregivers of children with 'autism disorder' aged 3 to 35 years old	To study caregivers' lived experiences while placing them in a relational, eco-systemic context	10
Dinnertime and bedtime routines and rituals in families with a young child with an autism spectrum disorder	Kylie Marquenie, University of Queensland, Australia	*Australian Occupational Therapy Journal*	2011	Thematic analysis of interview transcripts	14 Australian mothers with a young child with ASD between 2-5 years old	To provide occupational therapists with a description of the individual and collective experiences of dinnertimes and bedtime routines and rituals in Australian families with a child with ASD aged less than six. To depict challenges experienced by these families	9
Mothers' Challenges in Feeding their Children with Autism Spectrum Disorder—Managing More Than Just Picky Eating	Laura G Rogers, University of Alberta, Canada	*Journal of Developmental and Physical Disability*	2012	Semi-structured interviews using grounded theory	11 mothers of children with autism aged 4-11 years	What is the process of mothers feeding their children with ASD who have feeding challenges, and specifically what are the nature of these challenges	9
Phenomenological examination of the mealtime experience for mothers of children with autism and food selectivity	Michelle A Suarez, Western Michigan University, USA	*American Journal of Occupational Therapy*	2014	Phenomenological analysis of transcribed interviews.	4 mothers of children with autism aged 4-12 years with food selectivity	To learn about the experience of mealtimes from the perspectives of parent of children with autism and food selectivity	10
The everyday occupation of families with children with autism	Beth Werner DeGrace, University of Oklahoma Health Sciences Centre, USA	*American Journal of Occupational Therapy*	2004	Phenomenological analysis of transcripts of semi-structured interviews.	5 families of children with 'severe autism' aged 9-11	How does a family with a child with autism negotiate the occupations of being a family? What are the meaning they ascribe to these experiences?	10

2.3 Literature synthesis

The themes and subthemes from the results of each included study are listed in Table 4. These were manually sorted and grouped into categories to identify three overriding themes related to mealtimes and eating. Themes unrelated to mealtimes and eating were disregarded as out of the scope of the aims of the literature review:

2.3.1 Theme 1: Mealtimes are horrible

Co-occurring challenging behaviours in ASD cause stress to families and caregivers. In DeGrace's study of children with severe autism, this was explored in depth. Parents reported they feel robbed as a family, with sadness that the whole family life revolves around autism. One parent said "autism is a nightmare", another "nothing is easy" (DeGrace 2004). However, in Phelps' study some caregivers expressed psychological and social gains from having a child with ASD, although many also discussed negative emotional and financial negative impacts (Phelps et al. 2009).

Mealtimes are important times for many families. Nourishing a child is important to caregivers, giving feelings of satisfaction and confidence (Thorne et al. 1997). Mealtimes provide opportunities for shared family time, rich communication, and the development of shared family rituals and routines that support the maintenance and resilience of a healthy family unit (Fulkerson et al. 2008)

In Suarez's study parents expressed how unpleasant mealtimes could be, with them just "not working", family members often eating separately and completely different from how they had hoped before having their child (Suarez et al. 2014)

In Marquenie's study parents went even further, to describe mealtimes as absent of enjoyment, horrible and even "hell on earth". 92% (n=14) of participants described dinnertimes as "one of the most stressful times of the day" (Marquenie et al. 2011). Marquenie concludes that in supporting parents to develop better dinnertime routines, the development of a stronger family unit can be aided. (Marquenie, et al., 2011).

2.3.2 Theme 2: Given up on normalcy, caught up in child's idiosyncrasies

Across studies that explored mealtimes, mealtimes were 'different'. Marquenie discussed how mealtimes were focused around the child with ASD and their requirements: idiosyncratic details that must be met such as the 'right' cutlery, crockery, seating arrangements or presentation of the food; cooking separate meals for their child and the rest of the family; and the difficulty in getting the child seated to eat (Marquenie et al. 2011, Suarez et al. 2014).

Rogers' participants described how their child's eating habits are beyond picky eating, with restricted and often narrowing repertoires, a real need for sameness and sensory challenges "he gags at the smell of cooking" (Rogers et al. 2012).

Parents always tried to meet their child's need for idiosyncrasies as if they did notthere would be severe behavioural challenges "meltdowns". ASD was seen as the exception to the rule when it came to usual parenting at mealtimes; children were allowed to eat alone or have different foods (Marquenie et al. 2011). Parents reported giving up on various strategies they had tried as they had had no effect (Suarez et al. 2014).

2.3.3 Theme 3: Lack of support, lack of answers

Parents reported feeling let down by the lack of support for their children's eating problems. Rogers' reported concerns regarding their child's eating habits being wrongly dismissed by health care professionals as typical toddler fussy eating "when I say he doesn't eat, he doesn't eat" (Rogers et al. 2012). Suarez's participants reported that even when they could access professional support, contact was not regular enough or sustained for long enough to help with changing behaviours (Suarez et al. 2014).

Parents reported struggling through alone. Rogers' participants made sure their child had adequate intake and worked on increasing repertoire "I basically try to follow my own instincts" (Rogers et al. 2012). Suarez's participants expressed frustration trying to find out how to help their child. In trying to see the problem through their child's eyes they gained compassion for their child and recognised how difficult eating was for them (Suarez et al. 2014).

Lack of support was also a finding in Phelps' study, with an equal number of families reporting positive experiences of help from services (38%, n=80) as to those who expressed disappointment at lack of help from services. The need for more education about ASD for all professionals including medical ones was a key finding (Phelps et al. 2009).

2.4 Conclusion of literature review

This synthesis of five studies included 114 participants who were caregivers (mostly mothers) of children across the ASD spectrum aged 2-35, across three countries (Australia, Canada and USA). All studies were carried out with rigour. The synthesis met all ENTREQ criteria (enhancing transparency in reporting the synthesis of qualitative research see appendix 3) (Tong et al. 2012).

Limitations of the review included the use of key words for the initial literature search instead of Medical Subject Headings (MeSH). This may explain why the search only revealed 2 of the 5 subsequently included papers. A more extensive literature review including MeSH terms and expanded to quantitative studies and including other aspects of feeding problems would be useful but was out of the scope of this work.

Synthesis revealed three themes: 1) Mealtimes are horrible; 2) Given up on normalcy, caught up in child's idiosyncrasies 3) Lack of support, lack of answers. These support the author's clinical experience of parents of children with ASD and feeding problems.

Considering the preceding literature there seems to be a gap in the published literature around parental views on appropriate support that could be offered to support feeding problems.

This study will be the first to examine parental experiences of feeding problems in the UK, and the first to examine the experiences and needs of the patient group in Lewisham.

Table 4: Themes and subthemes from the studies included in the literature synthesis

Paper	Themes (* = unrelated to mealtimes)	Subthemes
(Suarez et al. 2014) (NB subthemes have been inferred from the text)	Unfulfilled hopes for mealtime as quality family time	Unpleasant mealtimes
		Separate mealtimes
		Incongruent experience of mealtimes to what they had hope
	Reasons for mealtime not working for the families	Difficulty sitting at table
		Difficulty getting their child to eat a variety of foods
	Strategies that are working to make mealtime a success or not	Given up on family mealtimes
		Need to attend to the mealtime environment
		Cooking multiple meals for different family members (exhausting)
		No success at getting child to sit at mealtimes despite different attempts
		Lack of sustained contact with professionals to assist
	Searching for answers	Compassion for the child with autism about difficulty at mealtime
		Trying to understand – frustrated with not knowing how to change
(DeGrace 2004)	Whole family life revolves around autism	Hectic lives
		Accrued stress
		Anticipation of challenging encounters
		'He has the run of the house'
	Robbed as a family	Hard to enjoy the day as a family

Paper	Themes (* = unrelated to mealtimes)	Subthemes
		Autism is a nightmare
		Nothing is easy
	*Occupy and pacify	Use of videos
		Use of home therapists
	Fleeting moments of feeling like a family	Difficult to identify times when they feel like a family
		Sadness about the impact of autism
(Rogers et al. 2012) (themes were described as 'core processes' rather than themes)	Recognising the feeding challenges	Patterns of onset
		Beyond picky eating
		Restricted and narrowing repertoire
	Defining the nature of the feeding challenges	Sensory difficulties
		Need for sameness
		Food jags
		Behavioural challenges
		Comorbidities
	Seeking support for and validation of the feeding challenges	Concerns dismissed by health care professionals
	Staging their approach	Initially ensuring adequate intake
		Moving beyond intake

Paper	Themes (* = unrelated to mealtimes)	Subthemes
		Increasing repertoire
(Marquenie et al. 2011)	Dinnertime: Centred on ASD	Focus on the child (Routines centred around child with ASD (with or without child) to cater for idiosyncrasies)
		Caught up in the child's idiosyncrasies (Idiosyncrasies around cutlery, crockery, demanding same chair and position + Behavioural challenges e.g. meltdowns when idiosyncrasies not met = Chaos)
		ASD: the exception to the rule (Not part of the family meal)
	Dinnertime: ASD alters meaning	Dinnertime is horrible (Nutrition concerns, Cooking multiple meals)
		Holding on (absent of enjoyment)
	*Bedtime: Centred on ASD	No problem as long as things happen (Routines, Accommodation of idiosyncrasies, Behavioural challenges e.g. meltdowns when idiosyncrasies not met)
	*Bedtime: ASD alters meaning	Bedtime all the colours of the rainbow (Moments of meaningful interaction, stressful)
		Trapped in routines
(Phelps et al. 2009)	*Psychological implications	Gaining psychological strengths
		Altruism in advocacy role
		Emotionally challenging
		Lack of answers to why child has autism

Paper	Themes (* = unrelated to mealtimes)	Subthemes
	*Familial implications	Built stronger connections
		Constant struggle
		Sibling neglect and jealousy
		Relationship with partner or spouse strained
	*Social implications	Developed new friendships
		Diminished opportunities
	*Services	Services (including school) help
		Lack of services providing help
		Frustration with education professionals not listening
		Need for more education for medical, judicial and educational systems
	*Spiritual beliefs	A source of strength
		Lack of understanding in their church
	*Economic challenges	Economic burden
	*Focus on future	Worry
		Acceptance

3.0 Methodology

3.1 Aims and objectives

This research aims to: examine the experiences of parents/guardians of children with ASD in Lewisham who have eating problems; the support they have received; and the additional support they would like.

The research questions are:

1) What are the experiences of parents/guardians of children with ASD in Lewisham who have eating problems of how the eating problem affects their child, their parents/guardians and their wider family?

2) What are the experiences of parents/guardians of children with ASD in Lewisham who have eating problems of the professional support they have been offered or received?

3) What further professional support would of parents/guardians of children with ASD in Lewisham who have eating problems in Lewisham like?

3.2 Research design

This research was placed within a pragmatic paradigm, designed without commitment to any one system of philosophy or reality, instead focusing on the best methods to answer the research problem.

Pragmatism rejects “the scientific notion that social inquiry was able to access the 'truth' about the real world solely by virtue of a single scientific method" (Mertens 2010). Ormerod’s examination of the history and philosophy of pragmatism argues it fits how practitioners behave in practice; it supports an empirical (scientific) approach; emphasizes the uncertain and changing nature of findings; recognizes the psychological nature of meaning; and places theory in the service of practice (Ormerod 2006).

Criticisms of a pragmatic paradigm is that it is the ‘hiding place for many positivists’ (Lincoln 2010). I have a background of a positivist positionality: my first degree was biochemistry which requires a realist standpoint; clinical

nutrition is positivist and realist; however, my positionality has changed through working in ‘the real world’ and recognising that knowledge is a relativist construct. To address ‘real world’ issues a flexible approach to using either or both qualitative and quantitative methods is needed. This study is exploratory and applied and fits the pragmatic paradigm ideally.

The research methods chosen to best meet the aims of the research were qualitative, to enable an exploration of real world experiences. The key steps of the research project are summarised in Figure 2 overleaf.

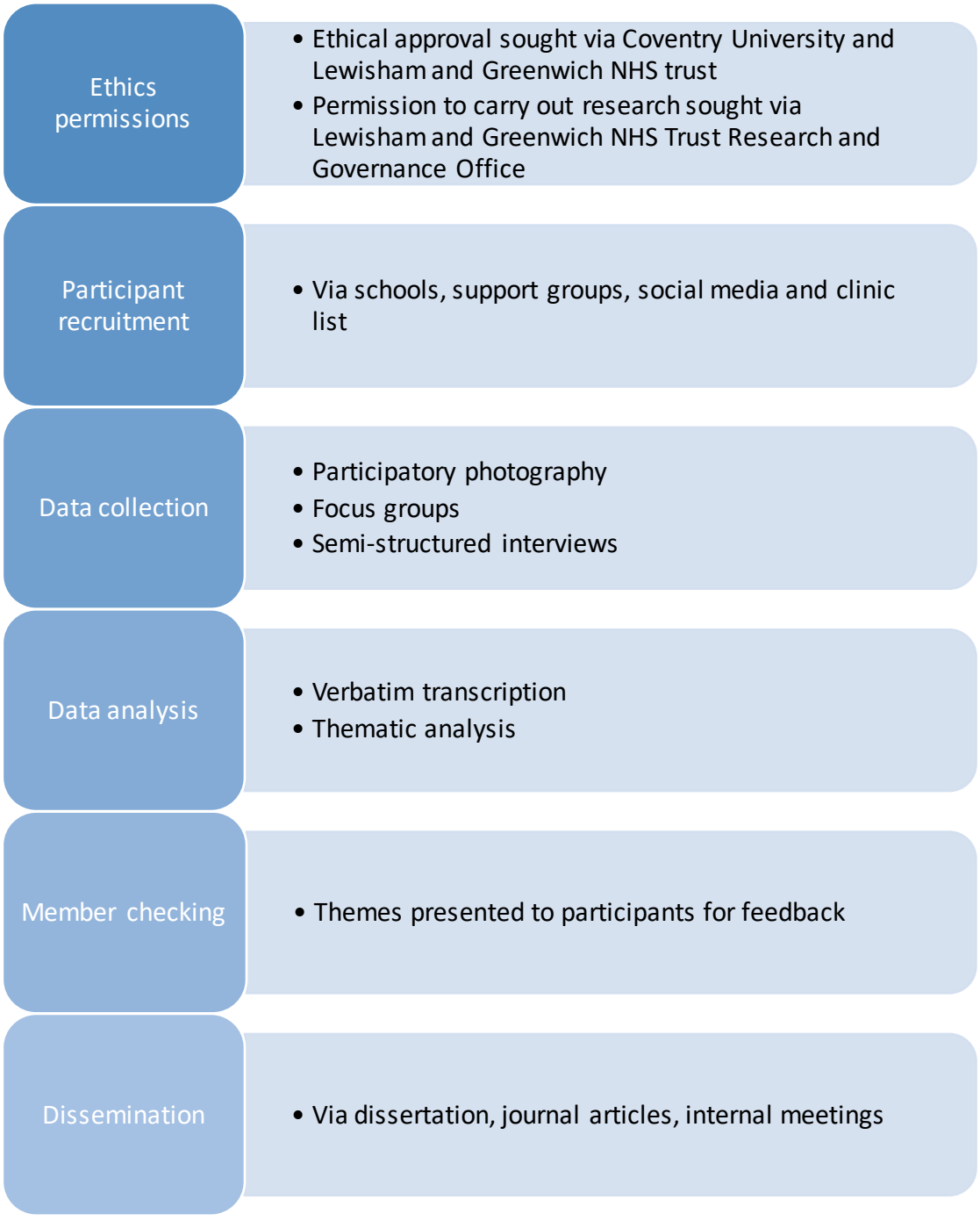


Figure 2: Key steps of the research project

3.3 Participants

Parents of children with ASD and a feeding problem were recruited for this study. Purposive sampling was used to include people with lived experiences relevant to the research (Patton 2002). We also used snowball sampling: asking participants to tell their friends.

3.3.1 Inclusion criteria

The inclusion and exclusion criteria for this study are below in table 5 below.

Table 5: Inclusion and exclusion criteria for the study

Inclusion criteria:	Exclusion criteria:
• Parents or primary carers of children (under 19s) who are diagnosed with ASD, live in Lewisham (defined as the Lewisham NHS services catchment area), and identify with their children having 'eating problems'	• Parents of children who do not have or are awaiting ASD diagnoses • Parents of children who live outside Lewisham (defined as the Lewisham NHS services catchment area) • Parents of children who have anorexia nervosa or bulimia nervosa

3.3.2 Recruitment

Participants were recruited by notifying parents of children with ASD in Lewisham via flyers and emails, via a multitude of routes:

- Flyers emailed to:
  - Administrators at all special educational needs schools in Lewisham for distribution to parents
  - The lead of Lewisham ASD parent support group Signal
  - The leads of medical, mental health, allied health and social services that support children with ASD in Lewisham
  - All staff in Lewisham and Greenwich NHS Trust
- Flyers were displayed:
  - In Lewisham Hospital
    - Childrens' A&E
    - Childrens' outpatients
  - In Kaleidoscope (Lewisham community clinic hub for children with special educational needs) waiting area and reception desks
- Social media
  - The author's Twitter feed
  - The author's Facebook feed
  - Lewisham Autism and ADHD Families Facebook Group (88 members)
- Direct contact with parents of children with ASD who were on the waiting list for or had attended the dietetic clinic for children with special educational needs at Kaleidoscope clinic in Lewisham. Contact was made via phone, text or email to ask if parents were interested in finding out more about the study. If so this was followed up by sending the participant information and follow up contact to gauge interest.
- Interested participants were encouraged to tell eligible friends about the study

Recruitment commenced in September 2016 and continued until the end of December 2016, with the above methods of recruitment repeated numerous times.

3.4 Data collection

Data was collected from six mothers of seven children with ASD via questionnaires, focus groups and semi-structured interviews, with an included aspect of participatory photography.

3.4.1 Demographics

Data regarding parent/guardian gender, age, ethnicity, child's age, ethnicity, age at diagnosis, coexisting conditions, ASD-related behaviours, eating behaviours and dietary intake were collected using a questionnaire (appendix 4). Consideration of collection of data related to maternal education, birth order of child, single parentage and others was made, to more thickly characterise the sample and thereby inform transferability, however these were not included to minimise the burden of data collection on the participants, as is ethically essential.

This questionnaire included the following measures to confirm eligibility, and to allow stratification of participants into more homogenous focus groups by type and severity of eating problems if numbers had allowed:

- The Childhood Autism Spectrum Test (CAST)
- Brief Assessment of Mealtime Behavior in Children (BAMBIC) (Hendy et al. 2013, Seiverling et al. 2016)
- Screening Tool of Feeding Problems in Children (STEP-CHILD) (Seiverling et al. 2011)
- 24-hour diet recall

3.4.1.1 The Childhood Autism Spectrum Test (CAST)

There is a dearth of validated, quick and easy tools to characterise ASD symptoms or severity, due to its complexity as a condition. Many tools available require expert observations and take a long time to complete. For the purposes of a pragmatic characterisation of the sample this free-to-use tool was included. CAST (previously the Childhood Aspergers Screening Test) is a 39-item questionnaire developed by the Autism Research Centre at Cambridge

University. It aims to identify children aged 4–11 years who are at risk of ASD (Scott et al. 2002). The maximum score is 31 with a cut off for suspicion of ASD of 15 (Allison et al. 2007).

3.4.1.2 Brief Assessment of Mealtime Behavior in Children (BAMBIC)

BAMBIC is 10-item questionnaire that results in scorings in three domains: food refusal, limited variety and disruptive behaviour (Seiverling et al. 2016).

BAMBIC is a modification of the Brief Autism Mealtime Behavior Inventory (BAMBI) (Lukens and Linscheid 2008), and has been validated in a sample of 356 non-clinic children in the US (mean age = 44.1 months; 58.7% male; 212 with no special needs, 58 with ASD, 86 with other special needs) (Hendy et al. 2013, Seiverling et al. 2016).

3.4.1.3 Screening Tool of Feeding Problems in Children (STEP-CHILD)

STEP-CHILD is a 15-item screening tool which results in scores on the six subscales of child feeding problems: chewing problems, rapid eating, food refusal, food selectivity, vomiting and stealing food (Meral and Fidan 2014, Seiverling et al. 2011). It has been validated in a sample of 142 children aged 2-18 years in the US (95 boys, 47 girls; mean age = 61.4 months; 43 with autism, 51 with other special needs, 48 with no special needs).

3.4.1.4 24-hour diet recall and Healthy Eating Index 2010

To enable a measure of dietary quality, participants were asked to list all the foods their child had eaten in the last 24 hours (24-hour diet recall). 24-hour recalls only capture one day's intake which may not be typical and reflect the mean dietary intake over a longer period of time (Falciglia et al. 2003), and rely on self-reporting, which has inherent margins of inaccuracy due to recall error and difficulties in reporting accurate portion sizes (Bingham et al. 1994). However, 24-hour recalls are quick, practical and accessible, and may be more reliable in children with feeding problems who only eat a limited range of foods and so were used pragmatically in this study.

The 24-hour recalls were used to calculate Healthy Eating Index-2010 scores. The Healthy Eating Index 2010 (HEI-2010) is a validated measure of diet quality, based on the 2010 Dietary Guidelines for Americans. These guidelines have been updated this year but the HEI-2017 is still under development. HEI-2010 consists of twelve scored components which are summed to yield a total score of up to 100. Normative data based on US-wide national food surveys are publicly available ((Guenther et al. 2007, 2008, 2013, 2014). Diet quality indices are relatively new to nutrition research and emerging research suggests they a useful tool to quantify risk of some health outcomes, including CVD, some cancers and mortality in adults (Wirt and Collins 2009), however, a lack of good quality evidence means their use to investigate and predict disease risk in children is as yet limited (Marshall et al. 2014). The US Dietary Guidelines for Americans and US intakes are close enough to UK government advice and UK intakes to be used in this study as a pragmatic scale to compare the 'healthiness' of the participants' diets in this study.

3.4.2 Focus groups

Focus groups were chosen as the first choice of data collection methods as the implicit interactivity can generate honest discussion, stimulate recall, unanticipated responses and validate through shared experiences (Braun and Clarke 2013, Pearson and Vossler 2016). Group discussion can foster creative thinking and solutions (Ritchie et al. 2014), and therefore fit the third research question regarding services parents desire, particularly well.

The aim was to recruit to up to six focus groups of six to eight participants. Ideal focus group sizes are from four to twelve participants (Then et al. 2014), with larger numbers providing the benefit of more stimulation of discussion, but being more difficult to moderate, particularly as a novice (Stewart and Shamdasani 2015). Six focus groups would achieve a balance between a feasible number to recruit and an estimate of the number needed to achieve a range of perspectives and data saturation (Braun and Clarke 2013). Focus group dynamics and resultant quality of data collected can be heavily influenced by group dynamics (Stewart and Shamdasani 2015). It was therefore planned to stratify participants into groups by age of child, abilities of child and

extensiveness of feeding problem, to increase the homogeneity of the groups, if numbers allowed.

Six participants initially responded to flyers and emails and expressed interest in attending focus groups. Unfortunately, it was not possible for all participants to attend at the same time and date, so the first group was due to include three participants, two mothers and one father of three different children with ASD.

The focus group was held at 10am on a Monday morning during school term time and hosted in a comfortable, private non-clinical room in the education centre of Lewisham Hospital, which has good public transport links, with refreshments provided. The author was the focus group moderator, with a pre-briefed student dietitian acting as assistant.

The focus group schedule is in appendix 5. This was designed with progression in type of questions (opening question, introductory questions, transition questions, key questions, and ending question) with care to start with less threatening questions and to build up to more emotive aspects (Krueger 2000) . Question topics drew on the studies identified in the literature review, and the author's clinical experience, to fully probe the issues related to the research questions, moving from asking about experiences of feeding problems to the support received and desired.

Unfortunately, two participants pulled out of attending within 24 hours of the session, one due to work commitments and one due to an urgent medical problem. The focus group then only involved one participant and so was conducted more as a semi-structured interview. At the start of the interview the participant was given the participant information (appendix 6), consent was taken (appendix 7) and the participant filled in the participant questionnaire. The interview lasted 45 minutes and was recorded using a digital audio recorder. After the participant had left, the interviewer and assistant discussed and made note of key thoughts and points that emerged from the session.

Due to the low response rate, it was not possible to arrange another group at a convenient time for more than one interested parent, so instead all those who

had been interested in attending focus groups were instead invited to take part in a phone interview at a time convenient to them.

3.4.3 Semi-structured interviews

It was predicted that recruitment to focus groups may be problematic in the target sample group for a couple of reasons: 1) practical barriers to attending: attending work or needing to care for their child with ASD or their sibling; 2) psychological barriers to attending; from clinical experience parents often seem somewhat ashamed of their child's eating problems, and find it difficult to talk about. A second choice of data collection, semi-structured interviews was therefore incorporated into the project plan and ethics application.

Semi-structured interviews allow participants to be asked the same questions within a flexible framework, utilising open-ended questions (Dearnley 2005). They can be carried out over the telephone at a time convenient to the participant, working around childcare and work responsibilities; and eliminate the possibility of participants' individual responses being diluted or changed by others' views, as could happen in a focus group (Belzile and Öberg 2012). However, interviews have a different dynamic, lacking some of the creativity fostered in group discussions (Belzile and Öberg 2012).

Two parents who had originally expressed interest in attending the focus groups agreed to be interviewed; thirteen other parents responded to adverts and invitations to take part.

Respondents were sent participant information sheets and consent forms either via email or by post depending on their preference, and given the chance to discuss any concerns further before agreeing to participate. Interviews were offered at a time and date convenient to the parent/guardian, being mindful of parents' other childcare or work commitments. Five out of the fifteen who expressed an interest consented and were interviewed. The others did not respond to further correspondence. One interview was carried out at 9pm on a week day, one at 10am on a Saturday and the remainder during normal working

hours. Interviews took 45-75 minutes and were recorded using a digital audio recorder.

The interview schedule is in appendix 8; this was adapted from the focus group schedule. Open-ended questions were used flexibly and changed or omitted where appropriate. One participant requested paper versions of the questionnaire and consent form (appendices 7 and 9) and posted them back to me, completed. The remainder filled these in on the secure online system Bristol Online Surveys. Consent and understanding of the participant information sheet were reviewed at the start of each interview.

Following each interview, A journal entry was made to reflect on main thoughts and key points of the interview.

3.4.4 Participatory photography

The incorporation of participant-provided photography is popular in health and social-care related research (Burles and Thomas 2014). Benefits of inclusion of images include the ability for participants to share personal and complex parts of their life that verbal language might not do justice; the ability to "express the unsayable"; sharing photos may help to empower participants; they also provide a focus for discussions, promoting engagement, and triggering memories; for the researcher and other viewers of the photographs they generate a richer understanding and empathy (Burles and Thomas 2014, Catalani and Minkler 2010, Dempsey and Tucker 1994, Drew et al. 2010, Thompson et al. 2008).

The level of consideration and reflection needed by the participant when employing participatory photography can be therapeutic particularly if reflecting on difficult times that have eased, however for participants struggling with their health or social issue, participation can be challenging (Burles and Thomas 2014, Oliffe and Bottorff 2007, Yi and Zebrack 2010).

Participatory photography was included for the following reasons: Firstly, to provide an extra layer of data to allow for triangulation, secondly as a conduit to elicit discussion in the focus group or interview; thirdly to yield rich and authentic data from each individual; and finally, to empower participants to be able to take

some ownership in the research process, honouring the value of their experiences.

Prior to the focus group or interview, participants were asked to submit to me via email or post five photographs that illustrated aspects of their child's eating problems, how they feel about their child's eating problems and how it affects them. As the interpretation of the meaning of any image is subjective (Packard 2008), it was key to ask participants to explain the meaning to them of their images. They were asked to provide a written caption for each one, explaining its meaning to me; the photos were then used as visual prompts and discussion primers within the interview.

The limitations of including participatory photography were considered carefully: it requires participants to have the equipment and ability to take photographs and challenges them to share sometimes intangible things visually. To ensure the burden of providing photographs and captions did not deter participants it was made clear that this aspect was optional. A detailed guide to the taking of photographs was adapted from existing Photovoice manuals (appendix 10) (Amos et al. 2012, Lorenz and Webster 2007) and participants were given the opportunity to discuss this aspect with me over the phone or email. The written guide included guidance on anonymity, consent and safety issues.

Ethical issues of including photography were carefully considered. The photography guide emphasised steps to avoid harm to themselves and others, for example the need to keep themselves safe when taking a photograph and not to take photographs of anyone else that might cause them harm or portray them in an unfair way. If other people were included in the photographs they or their parent should give full consent (form included in appendix 10) or be completely unidentifiable e.g. by only including the side or back of their head, or by pixelating their face. Participants were also asked to sign a photo release form authorising their use in the study and its dissemination (appendix 11).

All participants submitted photographs, but one only submitted two photographs without captions, and another submitted photographs and captions after their interview.

In addition to being discussion prompts the photographs and captions were analysed thematically. Visual qualitative analysis of the pictures as standalone data sources was not carried out as it is beyond the scope of the research questions and aim.

3.5 Ethical considerations and approvals

3.5.1 Ethical approvals

This study involved human participants therefore ethical approval was sought and granted from the Coventry University Research and Ethics Committee (appendix 12). The study did not involve randomisation or experimental research therefore did not need central NHS (IRAS) ethical approval (appendix 13). Lewisham and Greenwich Hospital NHS Trust research department advised that the study was a service evaluation and therefore it was registered and approved by the audit department (appendix 14).

3.5.2 Ethical considerations

Ethical consideration is key in any research. The following subsections detail how the main principles of ethics have been considered:

3.5.2.1 Benefits of research

The justification of this research is discussed in the introduction and literature review. The benefit to participants is that they were contributing to insights required to improve others' health. This was communicated to them in the participant information sheets (appendices 6 and 9).

3.5.2.2 Possible harm

The predicted possible harm to participants were threefold:

1) becoming upset during the discussion of their child's problems and the impact it has on them
2) realising their child had worse problems than already recognised and therefore experiencing resultant upset.
3) taking time away from caring for their child being a financial or emotional burden

A sheet collating websites and services to access for more help was prepared to provide at the end of an interview to mitigate the first two scenarios if they occurred.

The author's safety in conducting focus groups alone was considered and so these were only due to be carried out during office hours in a manned building.

3.5.2.3 Informed consent

Each participant was provided with a clear and detailed participant information sheet (appendices 6 and 9) prior to agreeing to take part and given ample opportunity to ask questions. Consent was reconfirmed orally at the beginning of the interview or group. Each participant initialled and signed a clear consent form (appendix 7).

3.5.2.4 Confidentiality/anonymity

The following steps were taken to protect participant data in line with the Data Protection Act (Her Majesty's Stationery Office 1998) and Good Clinical Practice.

- The raw data i.e. the audio files and demographic information that may contain identifying information were stored securely in a locked box in a locked room.
- Digital data was stored on an encrypted drive.
- Once transcription had been carried out the raw files were deleted.
- Participants and family members were assigned pseudonyms in the transcriptions to maintain anonymity.

3.5.2.5 Right to withdraw

Participant information detailed the participants' right to withdraw up to or during their interview or focus group. It would not have been possible to allow them to withdraw their consent after this data analysis was occurring concurrently and therefore this could jeopardise the completion of the project.

3.6 Data analysis

3.6.1 Thematic analysis

Thematic analysis was chosen as the most appropriate method of data analysis, from the numerous of approaches to qualitative data analysis that seek to describe patterns across the data. Interpretative phenomenological analysis was considered as an alternative; however its focus is on making sense of the meaning behind data, fitting more of a phenomenological or hermeneutic research standpoint (Brocki and Wearden 2006). This research has a more practical aim, exploring views of and desire for services; thematic analysis is a method of analysis that can fit many different research standpoints, making it an ideal choice for a pragmatist. Furthermore it has been described as the ideal starting point for early career qualitative researchers like me (Braun and Clarke 2006).

Inductive thematic analysis of the six interview transcripts plus the photographs and captions were carried out as in Figure 3, as per (Braun & Clarke, 2006) and detailed further below.

Figure 3: Inductive thematic analysis steps (Braun & Clarke, 2006).

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancester Library - Coventry University.

3.6.1.1 Step1: Familiarisation with the data

Excellent familiarisation with the data was achieved in conducting the interviews, transcribing the interviews, and reading and re-reading them to check the accuracy of the transcription. Reflections on identified patterns and potential themes were recorded in the journal.

3.6.1.2 Step 2: Generating initial codes

NVivo Pro 11 software (Qualitative Solutions and Research International, Doncaster, Victoria, Australia) was used for data management, data sorting and retrieval. Data collection and analysis occurred simultaneously, coding started after the first interview and as each subsequent interview was completed. After each interview, an anonymised version of the transcript, photographs and captions were imported into NVivo, then coded. The coding was carried out manually, ascribing 'nodes' on NVivo. An inductive approach was taken, coding all excerpts that seemed prescient, systematically working through the data set.

After the last interview and the initial coding of the complete data set, the process was repeated on all data sources to ensure no codes that had been identified in later data sources had been missed in the earlier ones. A journal

was kept throughout the data collection and analysis process to reflect on the process and emerging themes. 137 codes were identified.

3.6.1.3 Step 3: Searching for themes

Themes and subthemes were developed from the 137 codes identified in the data set. The initial theme map is in appendix 15 and includes three candidate themes: the feeding problem; help sought or desired; and special diet and supplement use; incorporating eleven sub-themes.

3.6.1.4 Step 4: Reviewing themes

Refining of themes and subthemes was carried out as per (Braun and Clarke 2006), starting with reviewing at the level of the coded data extracts. At the next level of refinement care was taken to consider the themes in relation to the entire data set. Detailed review of the journals was used to judge the fidelity of the candidate themes. This reflection along with feedback from the supervisory team on the initial theme map helped to produce a shift in themes, ensuring that the themes were an accurate representation of patterns across the data set. It was observed that the initial thematic map and particularly the three overriding themes had perhaps become more aligned with the initial research questions and resulting data collection questions, something that is highlighted as a key pitfall in thematic analysis (Braun and Clarke 2006). A repeat review of the refined themes at both levels ensured they had both internal and external heterogeneity.

3.6.1.5 Step 5: Defining and naming themes

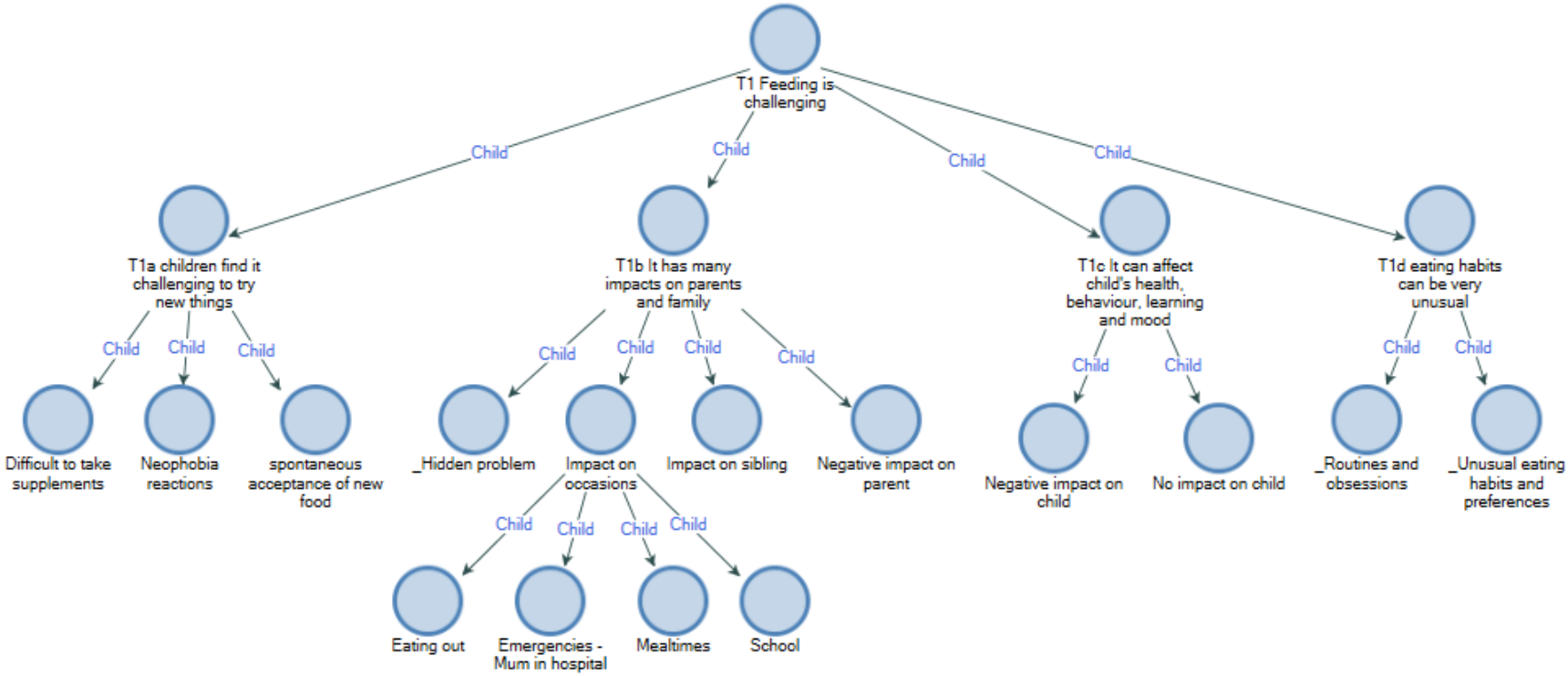
After obtaining a final thematic map of data (Figure 4 overleaf), this was reviewed and agreed by the supervisory team and feedback from member-checking (see section below). Care was taken to refine the names of each theme and subtheme to ensure they fully captured the essence of the content (Braun and Clarke 2006).

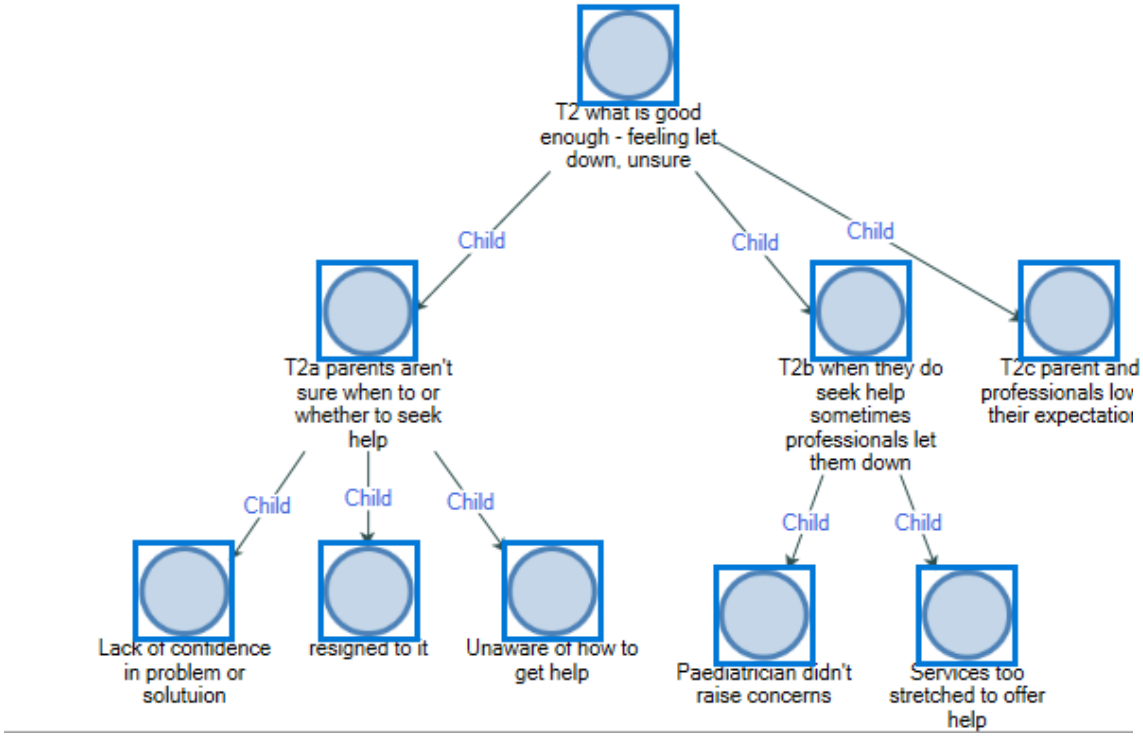
3.6.2 Member-checking

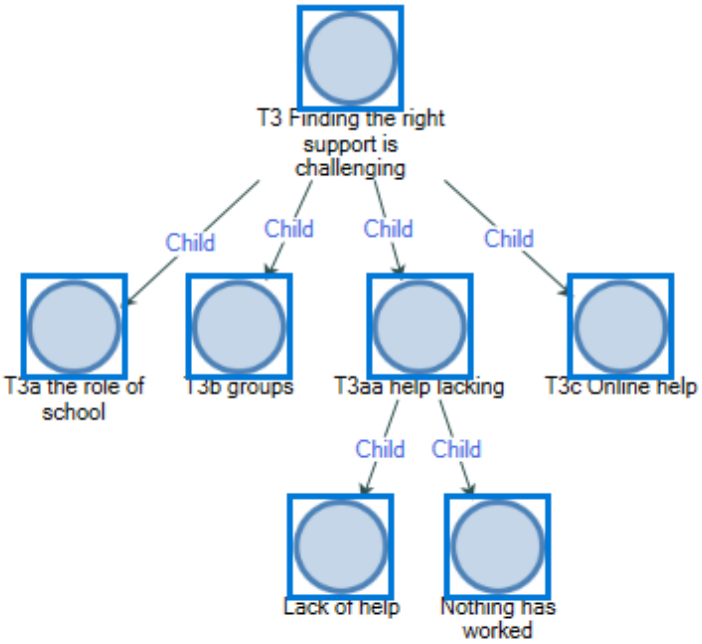
Member-checking adds to a study's credibility and involves asking participants to verify the researcher's interpretations. This happens at one or both the following stages: reviewing interview transcripts; reviewing the final findings. Member-checking minimises misinterpretations of participants accounts and actively involves participants in an empowering way (Goldblatt et al. 2011). Criticisms of member-checking are that it could feel exposing to participants; participants may change their mind about things over time; it could jeopardise anonymity, and instead of reducing it could reinforce the power differentials between the participant and researcher (Goldblatt et al. 2011).

The above risks were judged to be minimal in this research study and member-checking was carried out after thematic analysis had been completed via email correspondence. Four of the six parents responded to an email asking for their comments on the themes that had emerged from the research following step 4 of the above process. All of those who responded agreed with the themes and did not identify anything missing. The full member-checking responses are in appendix 16.

Figure 4: Refined maps for three themes




T2 what is good enough - feeling let down, unsure
Child
Child
Child
T2a parents aren't sure when to or whether to seek help
T2b when they do seek help sometimes professionals let them down
T2c parent and professionals lov their expectatio
Child
Child
Child
Child
Child
Lack of confidence in problem or solutuion
resigned to it
Unaware of how to get help
Paediatrician didn't raise concerns
Services too stretched to offer help


T3 Finding the right support is challenging
Child
Child
Child
Child
T3a the role of school
T3b groups
T3aa help lacking
T3c Online help
Child
Child
Lack of help
Nothing has worked

3.7 Rigour

Various strategies were incorporated into this study to optimise its rigour, using the trustworthiness criteria of credibility, transferability, dependability and confirmability (Guba and Lincoln 1989).

3.7.1 Reflexivity

Reflexivity is the process of examining both oneself as researcher, and the research relationship, throughout the research process is essential to maximise rigour. A researcher's 'conceptual baggage', their preconceived ideas, beliefs and prior experiences can have an influence on design, data collection and analysis (Kirby and McKenna 1989). The influence is particularly marked with qualitative research, where rich data collection can rely on developing good rapport and trust with participants. When previously unexamined a researcher's 'conceptual baggage' can have a negative impact when conducting data collection one to one, for example being caught off guard when a participant brings up a subject that is unexpected or in some way upsetting to the interviewer (Kirby and McKenna 1989).

Discussed below are aspects of my conceptual baggage identified prior to undertaking my research and taken account of throughout my research:

1) ASD and feeding problems have been my professional interests for many years. This benefits the study as I have a good understanding of ASD and various challenges commonly faced. A drawback is that I may miss some key points in being too close to the issue.
2) My personal agenda in carrying out the research is in hoping to provide evidence that parents struggle without an adequate dietitian service in Lewisham to: 1) make a good argument for going on to get PhD funding and 2) to give weight to continued pleas to commissioners to fund a better dietetic service. A benefit of this was that I am passionate about the subject, however I needed to take great care that my agenda did not bias the research. Prior to data collection I recorded a bias statement to identify prior assumptions the might affect the interpretation of the data. For example, it was anticipated that parents may report that mealtimes

are stressful, and they need more help than from existing services. The anticipated findings were evident in the results and so therefore I tracked the biases carefully by double-checking, discussion with my supervisory team, and member-checking.

3) I work as a dietitian in the area from which I recruited, which meant that I was familiar with ideal methods of recruitment and the local problems faced. The drawback was being close to the issues and having met and treated some of the participants before, which could cause a power differential and affect disclosure and rapport.
4) I am a well-educated, white, middle class woman in my 40s, with an accent that to some may sound 'posh'. For participants that have similar characteristics to me, this may build rapport and trust and disclosure in the interview however conversely for other participants their constructed view of me due to these characteristics may make me feel like even more of an 'outsider' and adversely affect our interviews.

3.7.2 Journaling

Throughout the study, an electronic journal was kept that included field notes, personal reflective and reflexive notes (Rose and Webb 1998, Tuckett and Stewart 2004). This included immediate perceptions and feelings after interviews, reading new papers or coding each data source. An audit trail was also kept via reporting logs from NVivo.

During data analysis, continually checking with the journal was used to mitigate against potential sources of bias e.g. by discussing these in my supervisory team and ensuring my interpretations were reflective of the data rather than my preconceived ideas. This meticulous process contributed to the credibility and dependability of the study.

3.7.3 Thick description

For qualitative research findings to be transferable the reader needs to have a thick or in-depth description of the methods used and the characteristics of the participants. This also impacts the dependability (Krefting 1991, Tuckett 2005). Use of journaling ensured that each step in the process was well documented. Care has been taken to ensure that the descriptions of the methods and the participant characteristics in the results are 'thick' enough.

3.7.4 Triangulation

Triangulation "strengthens a study by combining methods. This can mean using several kinds of methods or data, including using both quantitative and qualitative approaches" (Patton 2002). Triangulation of methods was incorporated by the inclusion of participatory photography, allowing distinct types of data from the same sources. Due to resource constraints, it was not possible to have data collection, coding, and data analysis carried out by other researchers, however an element of investigator triangulation was used by sharing transcripts and each step of the thematic analysis with my supervisory team for checking and discussion. Other activities that triangulated my findings were the inclusion of member-check, and the use of journaling. These multiple aspects of triangulation increase the confirmability, dependability and credibility of the study and its findings.

4.0 Results

4.1 Participant characteristics

Detailed characteristics of the six participants are described below. All are mothers in their 40s, and their seven children with ASD are aged six- to thirteen-years-old, two are girls and five are boys. Participants' identities and those of their children are protected by using pseudonyms.

4.1.1 Participant 1: Jenny and Jack

Participant 1, Jenny was 46-years-old and the mother of Jack. Both are white British. Jack was twelve-years-old and was diagnosed with Asperger's three years ago. Jack's eating problems "aren't severe and they wouldn't be noticed by a lot of people". Jack scored just below the ASD-suspicion cut off on the CAST scale (see table 6). His scorings on all the feeding behaviour dimensions were within the normal ranges for children with ASD, but to the lower end of the ranges (indicating lower concern in these areas) (see table 6). Jack's HEI scores indicate his diet quality is lower than for the general population mean, with a particularly low intake of wholegrains and non-dairy protein-rich foods and a high intake of sodium. However, he does eat plenty of fruit and vegetables (see table 7).

4.1.2 Participant 2: Becky and Ben

Participant 2 was Becky, the 41-year-old mother of Ben. Both are white British. Ben is six-years-old and was diagnosed with ASD when he was four. Ben ate well when he was a baby but at about 18-months-old became poorly and gradually stopped eating a lot of things, until his choices were quite restricted. "It never improved – in fact it got worse... he'll only eat a handful of things". Ben scored below the ASD-suspicion cut off on the CAST scale (see table 6). His scorings for food refusal and chewing problems were lower than the normal range, indicating these problems were milder, however his scorings on the rest of the feeding behaviour dimensions were within the normal ranges for children with ASD, with his limited variety score being the highest in the group (see table 6). Ben's HEI scores indicate his diet quality is lower than for the general population mean, and one of the lowest in this study. He does not eat any fruit

and vegetables, and has a high intake of sodium. However, he does eat ample wholegrains, seafood and plant-based protein-rich foods (see table 7).

4.1.3 Participant 3: Clare, Christopher and Carl

Participant 3, Clare is the 44-year-old mother of two children with ASD. Christopher was nine and was diagnosed with ASD at three-years-old. Carl is seven and was diagnosed with ASD at two-years-old. All 3 are white British. Christopher and Carl are quite different: Christopher "is a hundred miles an hour... he is up the walls and around the corners before you've even opened your eyes."; whereas Carl is much calmer and quieter and is "non-verbal". Both their diets "are really restricted".

Christopher scored well above the ASD-suspicion cut off on the CAST scale (see table 6). His scorings for food stealing were higher than the normal range, indicating this problem was more pronounced, however his scorings on the rest of the feeding behaviour dimensions were within the normal ranges for children with ASD, with his limited variety score being one of the highest in the group (see table 6). Christopher's HEI scores indicate his diet quality is lower than for the general population mean, and one of the lowest in this study. He does not eat any greens and beans or wholegrains and has a high intake of empty calories. He does however eat other fruit and vegetables and has a good intake of dairy and other protein-rich foods, and a moderately low intake of sodium (see table 7).

Carl scored well above the ASD-suspicion cut off on the CAST scale and slightly higher than his brother (see table 6). His scorings for chewing problems, rapid eating, food refusal and stealing food were above the normal range for children with ASD, indicating these problem behaviours being more frequent or more problematic. His scorings on the rest of the feeding behaviour dimensions were within the normal ranges but higher than the mean for children with ASD (see table 6). Carl's HEI scores indicate his diet quality is lower than for the general population mean, but one of the highest in this study. He does not eat any vegetables, but does have a good intake of fruit, wholegrains, dairy and protein-rich foods and his sodium intake is low (see table 7).

4.1.4 Participant 4: Dee and David

Participant 4 was 45-year-old Dee, the mother of David. David was seven-years-old and was diagnosed when six-years-old. Both Dee and David are white British. He's "easily overwhelmed and easily distracted by things, and has obsessions and fixations on things", and "an extremely fussy eater".

David scored well above the ASD-suspicion cut off on the CAST scale and the highest in the group (see table 6). His scorings for disruptive behaviour and food refusal and stealing food were above the normal range for children with ASD, indicating these problem behaviours being more frequent or more problematic. His scorings on the rest of the feeding behaviour dimensions were within the normal ranges for children with ASD (see table 6). David's HEI scores indicate his diet quality is lower than for the general population mean. He does not eat any greens and beans nor non-dairy protein-rich foods, but does have a good intake of other fruit and vegetables and dairy foods and his sodium intake is moderate (see table 7).

4.1.5 Participant 5: Kay and Eva

Participant 5, Kay was 45 years old and the mother of Eva. Eva was eleven-years-old and was diagnosed with "autistic spectrum" when three. She also has other genetic conditions and developmental delay. Kay and Eva identify as being "any other white background". Eva has had feeding problems from birth: "she was never fond of eating". She has a rigid sense of the food she will and will not eat and rarely deviates from these.

Eva scored well above the ASD-suspicion cut off on the CAST scale, the third highest in this study (see table 6). Her scorings for food refusal were below the normal range for children with ASD, indicating these behaviours are milder or less frequent, however her chewing problems score was the highest in the group and above the normal range for children with ASD. Her scorings on the rest of the feeding behaviour dimensions were within the normal ranges for children with ASD (see table 6). Her HEI scores indicate her diet quality is much lower than for the general population mean, the lowest in this study. She does not eat any fruit, greens and beans, and has a high intake of sodium,

however she does eat a small amount of other vegetables, and moderate amounts of dairy and other protein-rich foods (see table 7).

4.1.6 Participant 6: Fiona and Fay

Participant 6 was Fiona, the 48-year-old mother of Fay. Fay was 13-years-old and was diagnosed with ASD when 2 ½ years old. She had feeding problems from birth. She was tube fed as a baby due to not latching on, and not weaned off the tube until 3 ½ years old. She still has some problems with eating including gagging a lot and needing food to be the 'right size' to eat it. Fiona identifies with being white British, and Fay as "any other mixed background". Fiona says of Fay "I think she is awesome. I learn from her every day. She's wired up differently, obviously, but incredible… She's the happiest child, I've ever met."

Fay scored well above the ASD-suspicion cut off on the CAST scale (see table 6). Her food refusal score was below the normal range for children with ASD, indicating this behaviour was milder or less frequent. Her scorings on the rest of the feeding behaviour dimensions were within the normal ranges but higher than the mean for children with ASD (see table 6). Fay's HEI scores indicate her diet quality is lower than for the general population mean, but the best in this study. She does not eat any greens and beans or wholegrains, but does have a good intake of fruit, other vegetables, dairy and protein-rich foods and her sodium intake is low (see table 7).

4.2 ASD and eating behaviour scores

The CAST, BAMBIC and STEP-CHILD scores for each participant's child are displayed Table 6. The bottom rows indicate the sample median and range scores, and the normal ranges established in the supporting literature.

The participants' children had a range of CAST scores: with two (Jack and Ben), falling below the level which warrants suspicion of ASD and the remainder being towards the higher end of the scale (Allison et al. 2007, Scott et al. 2002).

The children had a range of scores within the BAMBIC and STEP-CHILD dimensions. For the three BAMBIC dimensions, three had food refusal scores higher than the mean for children with ASD (established from a sample of 60

(Hendy et al. 2013, Seiverling et al. 2016,)), but within one standard deviation of the mean. One was lower but within one standard deviation of the mean and two were more than one standard deviation than the mean. All had scores within one standard deviation for limited variety, and all but one were within one standard deviation of the mean for disruptive behaviour. David had a disruptive behaviour score more than one SD above the mean for children with ASD.

For the six STEP-CHILD dimensions the participants' children also had a range of scores. All the scores for food selectivity and vomiting dimensions were within one standard deviation of the norm (established from a sample of 142 children referred to a hospital-based feeding clinic, 43 of whom had autism (Meral and Fidan 2014, Seiverling et al. 2011)). Several children had scores higher than one standard deviation above the mean: one in rapid eating, two in food refusal, two in chewing problems and three in stealing food. Carl had scores higher than one standard deviation above the mean for four of the six dimensions.

4.3 Diet quality scores

All participants' children's diet quality scored below the population average for children in the US on the Healthy Eating Index-2010. A breakdown of the scoring of the different dimensions of the HEI-2010 is below in Table 7 on page 55. The mean scores from US population data are shown in the final column.

The nutrition status of children in the US is close enough to that in the UK to be comparable. Many of the children had whole food groups missing from their day's diet e.g. eating no fruit and vegetables or no protein-rich foods. This is a nutrition concern independent of the total HEI-2010 score as diets lacking in whole food groups are more likely to be lacking in key nutrients.

Table 6: Participants' child's scores on the CAST (Childhood Autism Spectrum Test), BAMBIC (Brief Assessment of Mealtime Behavior in Children), and STEP-CHILD (Screening Tool of Feeding Problems in Children) scales. Shaded cells highlight scores outside the 'normal range', or for CAST, lower than the threshold for suspicion.

Participant Number and Child's Pseudonym	**CAST Score**	**BAMBIC Dimensions**			**STEP-CHILD Dimensions**					
		Food Refusal score	**Limited Variety score**	**Disruptive Behaviour score**	**Chewing Problems**	**Rapid Eating**	**Food Refusal**	**Food Selectivity**	**Vomiting**	**Stealing Food**
1 – Jack	13	2.0	3.8	1.0	0.33	0.33	0.67	1.50	0.00	0.00
2 – Ben	10	1.7	5.0	1.0	0.00	1.00	0.67	1.50	0.00	0.50
3a - Christopher	24	3.3	4.8	1.3	1.00	1.00	1.33	2.00	0.00	1.00
3b – Carl	27	3.7	4.8	2.7	1.33	1.33	1.67	2.00	0.00	2.00
4 – David	28	4.0	4.0	3.7	1.00	0.67	1.67	2.00	0.50	1.00
5 – Eva	26	1.7	4.5	1.3	2.00	0.67	0.00	1.00	0.00	0.00
6 – Fay	24	1.0	4.3	1.0	0.33	0.33	0.67	1.50	0.50	0.00
Median	***24***	***2.0***	***4.5***	***1.3***	***1.00***	***0.67***	***0.67***	***1.50***	***0***	***0.5***
Range	***10-28***	***1.0-4.0***	***3.8-5.0***	***1.0-3.7***	***0-2.00***	***0.33-1.33***	***0-1.67***	***1.00-2.00***	***0-0.50***	***0-2.00***
Notes on typical range	ASD suspicion cut off 15. Maximum score 31	Normal (ASD) 2.97 SD +/-1.01 Normal (NT) 2.7, SD +/-1.01	Normal (ASD) 4.3, SD +/-1.03 Normal (NT) 4.0, SD +/-1.0	Normal (ASD) 2.03, SD +/-1.1 Normal (NT) 1.6, SD +/-0.9	Normal 0.48, SD +/-0.58	Normal 0.46, SD +/-0.47	Normal 0.87, SD +/-0.54	Normal 1.53, SD +/-0.68	Normal 0.39, SD +/-0.46	Normal 0.24, SD +/-0.47

Table 7: Participants' child's HEI-2010 (Health Eating Index 2010) scores (shading indicates scores less than 25% of the full score for each component and those below 40 for the total score)

HEI-2010 Dietary Component (maximum score)	**Participant 1 - Jack**	**Participant 2 - Ben**	**Participant 3a - Christopher**	**Participant 3b - Carl**	**Participant 4 - David**	**Participant 5 - Eva**	**Participant 6 - Fay**	***Median***	***Range***	**Children 2-17 years (n=2,857) - mean score in 2011-2012 (standard error) (Data source: National Health and Nutrition Examination Survey, 2011-2012)**
Total fruit (5)	5.0	0.0	4.8	5.0	5.0	0.0	2.7	***4.8***	***0-5.0***	3.91 (0.18)
Whole fruit (5)	5.0	0.0	5.0	5.0	5.0	0.0	5.0	***5.0***	***0-5.4***	4.78 (0.22)
Total vegetables (5)	3.5	0.0	4.2	0.0	5.0	1.5	4.9	***3.5***	***0-5.0***	2.10 (0.09)
Greens and beans (5)	5.0	0.0	0.0	0.0	0.0	0.0	0.0	***0***	***0-5.0***	0.70 (0.09)
Whole grains (10)	0.0	10.0	0.0	5.7	2.2	0.0	0.0	***0***	***0-10.0***	2.50 (0.10)
Dairy (10)	6.0	2.7	10.0	8.2	10.1	8.9	10.0	***8.9***	***2.7-10.1***	9.03 (0.22)
Total protein foods (5)	1.5	1.4	5.0	2.5	0.0	5.0	5.2	***2.5***	***0-5.2.0***	4.44 (0.13)
Seafood and plant proteins (5)	1.6	4.4	0.0	0.0	0.0	0.0	0.0	***0***	***0-4.4***	3.05 (0.17)
Fatty acids (10)	0.0	0.0	2.0	2.0	0.0	2.0	2.0	***2.0***	***0-2.0***	3.29 (0.18)
Refined grains (10)	10.0	10.0	4.0	5.0	10.0	10.0	4.0	***10.0***	***4.0-10.0***	4.91 (0.16)
Sodium (10)	0.0	0.0	5.0	10.0	5.0	0.0	9.0	***5.0***	***0-10.0***	4.85 (0.25)
Empty calories (20)	4.7	11.0	0.0	4.4	0.5	5.2	4.9	***4.7***	***0-11.0***	11.50 (0.28)
Total HEI score (100)	**42.3**	**39.5**	**39.5**	**47.8**	**42.9**	**32.7**	**48.2**	***42.3***	***32.7-48.2***	**55.07 (0.72)**

4.4 Thematic analysis

Transcriptions of the participant interviews, and their submitted photographs and captions are in appendices 17 to 28.

Five themes were identified from this research:

1. Difficult mealtimes
2. Unsure when or whether to pursue help
3. Lowered expectations of parents and professionals
4. Feeling let down by a lack of support
5. Services must be easily accessible and supportive

Table 8 lists the themes, subthemes and codes within each.

4.4.1 Theme 1: Difficult mealtimes

It is unsurprising given that all participants were recruited due to feeling their children had eating problems that all participants expressed that mealtimes with their children with ASD were difficult. All participants gave many rich examples of this. This theme captures not just the nature of the difficulties but also the impact these difficulties have on the children and families. This theme incorporates four subthemes:

Subtheme 1a: Unusual eating habits

All participants described eating routines and habits that are unusual compared to children of a similar age. All parents described a rigidity around the range of foods they would eat which far exceeds typical fussy eating. Some had unusual and rigid food preferences when it came to individual food presentation.

> *""This first picture shows the main foods that Ben eats. The second is a picture of some toast. […] On a typical day, at the moment in the mornings normally its always toast with Nutella, it has to be almost... at the moment it has to be almost cremated... its really really burnt […] he'll like examine it. I have to make sure the burnt side is on the side that*

hasn't got the Nutella, because he inspects it basically, underneath, and if it isn't as burnt he'll put that bit in the - in the bin. […].”.”

Others had rigid preferences for where they ate as well as what they ate,

“Frankfurters for breakfast every day. Mayo and fork and knife. No bread. On the table has to be two cups. One animal one with water and dinosaur one with mint tea. On the side table is story played on tablet. It is every day the same set of Fairy Tales volume 2 and 1. Breakfast is always eaten at the small table sitting at her bed.”

The use of separated plates was apparent in three of the six participants’ photos. Participants descriptions of mealtimes ranged from boring to chaotic, but never enjoyable:

“Extremely disruptive, very chaotic, […] he's very volatile, very unpredictable so sometimes he'll be, um, you know, screaming. […] he's very messy […] he's just you know always got this sort of agitation about

him"

Subtheme 1b: Trying new food is challenging

All participants reported that their children found new food a challenge.

This photo and caption was of the first time one child tried a new dish:

> *"I can't count how many times we have tried this. Christopher will get extremely upset, screaming and protesting, pushing everything away. Made me feel like I'm force feeding him. It was very tense for a while and the food was pretty cold in the end but with lots of praise and encouragement, he tried it...."*

Another participant explained how fussy their child is:

> *"He'll go through phases of wanting the same meal over and over and over again, then he'll go back to another sort of common meal that he used to eat but it's very difficult to introduce new foods to him"*

Responses to being offered new foods were just to ignore it to getting really upset.

> *"He will get extremely upset, screaming and protesting, pushing everything away. Made me feel like I'm force feeding him."*

Subtheme 1c: Eating problems affect children's health, behaviour, learning and mood

All participants felt that the eating problems had negative impacts on their children. Children got very hungry or thirsty due to food refusal and the effects of this varied from struggling to concentrate at school to more challenging behaviours. These quotes are from three different participants;

> *"He'll get extremely, um, start having a panic attack and screaming […] he won't be able to say sometimes that he's thirsty, he just needs to drink you know and he'll have extremely violent, angry, aggressive behaviour."*

> *"When she was hungry, she didn't like to eat anything else and then, when she was hungry she was unbearable. Her behaviour was unbearable. Was frustrated, throwing things, she wasn't happy with anything. Obviously, because she was hungry. But she refused to eat anything else,"*

> *"He was often sort of hungry at school so not being able to work properly and getting quite agitated."*

Two children suffer from chronic severe constipation that their parents attribute to their poor diet and cause their children distress.

Four parents reported that their children exhibited challenging behaviour when distressed by merely being exposed to certain foods in their environment.

> *"a smell can kind of completely throw him you know and sort of make him panic almost you know, […] he'd run off generally […] Just escape, escape".*

"he has strong and angry reactions to butter. If he feels-- if he thinks-- he detects or smells his food and he'll get quite a bit paranoid actually that there's butter in there.

Subtheme 1d: Eating problems impact on parents and families

All parents discussed ways in which their child's eating affects them as parents and the wider family.

All mothers reported negative impact on their wellbeing;

"It's exhausting. I am so drained and so exhausted. […] it's almost like having a baby that never grows, […] it's a constant worry, you know, it's a constant anxiety to me."

Two participants expressed concerns that their younger children copied their older siblings diet and as a result had a poorer dietary variety.

Three participants highlighted that their child's eating habits affect their entire family in limiting social food related activities. The photograph below and caption illustrates this.

"This is from a recent holiday. He is resistant to sitting in a big group. The people behind him are his cousins and uncle and aunt, but he would find it hard to sit at the same table as them. Mealtimes are always a stress point on holiday - I get upset because it should be enjoyable but it is never relaxed."

Two parents shared a sense of guilt and self-blame for their child's eating problems,

> *"The first thing you do is sort of assume that you are making mistakes somehow, or you're doing something wrong. Um, and I think that did burden us quite a lot for many years really."*

Five of the parents expressed worries about the adequacy of their child's dietary intake.

> *"I think he's physically not getting everything that he should get because he doesn't eat any fruit or veg, he has no dairy […] - it does worry me."*

Another participant highlighted the extensive time spent catering for her child's preferences;

> *"that could take me about an hour to prepare, cooking the sausages and then you know - and then peeling them, takes about an hour really, and you know, I try to peel them as carefully as I can but obviously some of the sausage gets taken away because there's peel in them, but yeah, it can take about an hour to do and as soon as I give it to him, he's like, "Mummy I'm finished."*

4.4.2 Theme 2: Unsure when or whether to pursue help

One parent expressed high satisfaction for the service received and had received help almost uninterrupted since birth due to her child needing tube feeding in infancy.

All other parents had been unsure when to or whether to seek help from professional services regarding their child's eating. Parents were unsure as to whether their child's eating problems were severe enough to seek help, because their weight was not faltering.

> *"I could never been to the doctor and said, "I am worried about Jack's eating." Um, because of, you know he's never been worryingly underweight or anything like that. […] when you talk about these things, sometimes I feel like I'm still talking about things that are a bit trivial because they're not, you know, Jack's not -- He's not malnourished.."*

> *"So his eating problems aren't severe and they wouldn't be noticed by a lot of people. And I just hope that's not a problem because I'm definitely aware of them,"*

Two parents reported they had considered getting help but had given up as they did not know how to access help:

> *"perhaps I should have tried harder, um, but life was hard enough it was one of the things that probably fell through the net, d'you know what I mean?"*

> *"I didn't ever think, um, I think I was too busy blaming ourselves so I didn't ever think it was someone -- anyone else could help [laughs]."*

4.4.3 Theme 3: Lowered expectations from parents and professionals

Part of the underlying reasons for the unsureness about whether to seek help (theme 2) rested on a general lowered expectation for eating in children with ASD, from parents and sometimes from professionals too:

> *"everyone just takes it for granted that your children will eat whatever and, um, you know and you just sort of - I think, oh well, we've got a child who doesn't really and has got a really restrictive..."*

> *"everybody said, "Oh, you know, it's not too bad because other children, they will eat only, you know, one type of crackers only."*

"I would like it if I went to the doctor with any concerns that they would take that seriously."

Parents doubted whether professionals would take their concerns seriously and seemed resigned to dealing with their children's eating problems without professional help.

"We did seem to sort of muddle through on our own, […] but then it got to a stage where, you know, it's not good at all, really."

"I thought, 'well what are they going to say? They'll say he does eat this and he does eat that.' […] I just got on with it."

One parent recalled a time when she had sought help during her child's annual check by the paediatrician in her school:

"she was in a period that she has eaten like 10 eggs a day and she didn't like to eat anything else. And one of the doctors in, uh, one, um, one of the consultations, um, I said, you know, she's eating all the time the-the eggs and he said, "You know, it's fine. You don't have to worry about it.""

4.4.4 Theme 4: Feeling let down by a lack of support

Other than the one parent who felt she had had excellent support all through her child's life, all parents felt there was a lack of available support, and had a feeling of being let down.

"I haven't seen anybody about him, I've just done everything indoors, just pulled my hair out now and again to my husband."

One parent expressed frustration with the service provided by the dietitians in Lewisham community services (the author's service as a clinician). She was referred but was put on a long waiting list and was never offered an appointment. Another felt let down by the same service:

"I had one appointment and because he didn't really have any problems, they discharged him from the service. […] because their service was so stretched"

Another parent felt a key point was that her child's school failed to report to her the eating problems at lunch times for many years. She found out about them much later:

"He didn't have packed lunch until he was about, I think it was when he was about eight. I suddenly sort of realised that he wasn't, he hadn't been eating school dinners at all"

4.4.5 Theme 5: Services must be easily accessible and supportive

When asking parents about which services they desired, many struggled, partly because many were notsure if their child's eating warranted help. Others doubted how helpful any support could be:

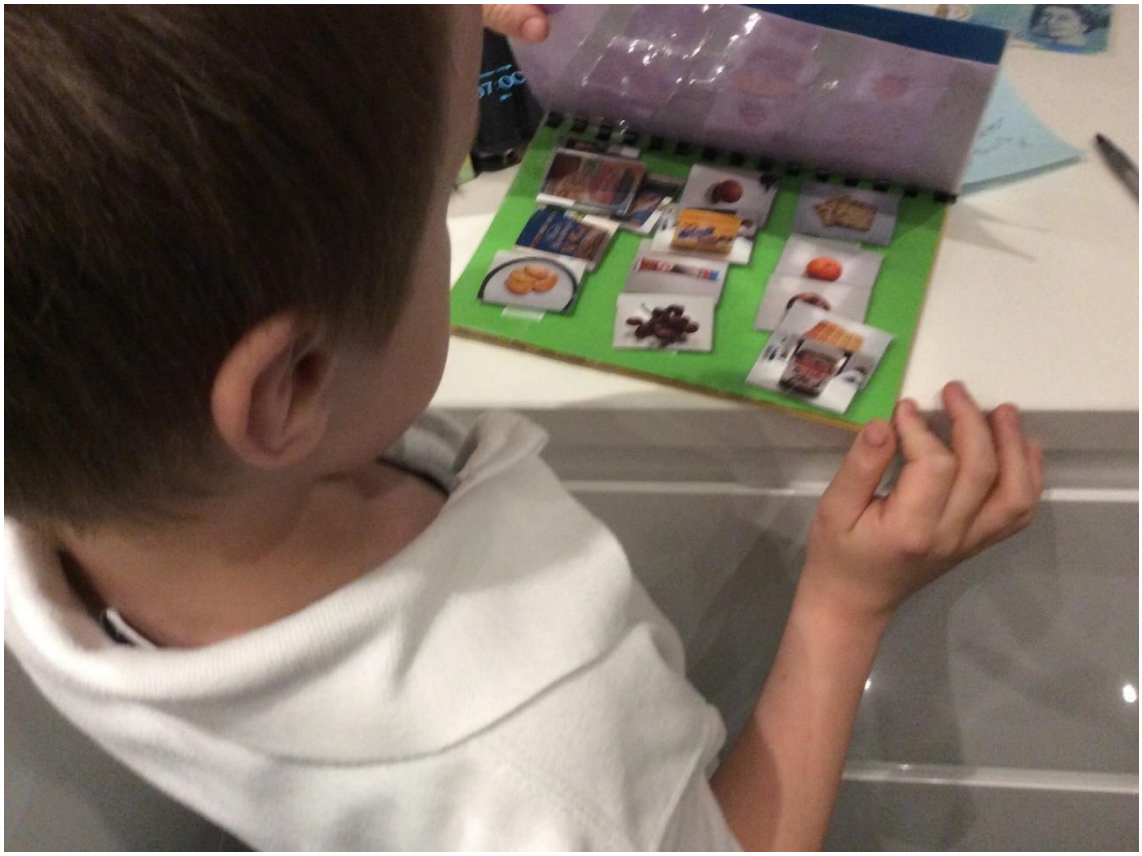
"I'm not prepared to stand here and cook four dinners, either. Do you know what I'm saying? For each one of them to go in the bin? So, um-- I don't know if that sounds really harsh, but I suppose that's what I-I-I-I- I don't want, um-- When someone tells me "do this," or "do that," I might not have took to that. Does that make sense?"

The data is arranged into the different services discussed by parents below:

Subtheme 5a: The role of school

Four parents talked about potential and previous support from schools. One parent highlighted that her child's mainstream school could have helped with his eating: better monitoring of intake at mealtimes; modification to his mealtime environments; and improved food quality provision. Three parents felt their child's schools had helped to find ways to manage underlying issues related to eating, for example introducing pictorial choice resources around food (see photo below), and help in writing social stories. Two parents reported that food technology sessions were successful in helping their children try new food in their respective schools.

"Food Tech is certainly helping, because she's cooking different meals and she's done a stir fry this week with green peppers. They did that on Monday, and she's eaten some of it! I can't believe it, wonderful! Onions and green peppers in this stir fry, and she's eating it, it's fantastic! So, if she's cooking it, she'll eat it."



Subtheme 5b: A 'super-nanny' service

Two parents discussed how helpful a one to one home visit service would be.

> "In any of it, not just food, when they're having a meltdown, when you can't get them to bed, you just want someone to come in and help you"

Subtheme 5c: Group sessions

The option of group sessions to help with their children's eating problems was discussed by a few parents, and there were mixed feelings about this. One felt these would be very useful and she would be keen to attend, to share experiences with others that understood. Two felt groups were great in theory but would be unable to attend due to work and childcare.

> *"Just meeting other, sort of, parents new to the area or whatever who's going through the same, same thing as what we are really would be, would be useful, yeah."*

> *"I found it very difficult to access courses, um, you know, without, you know, childcare, you know, that's always been the problem because it's,*

you know, they're extremely needy-- they have extreme needs, you know. So it's very difficult"

Subtheme 5d: Online help

Access to online help was explored with some parents. One would not use this due to not liking being online, however two were interested, particularly as access would be flexible alongside work commitments. Another felt that curated content would be great, as she often sought help online but,

"I feel very overwhelmed when I look online. I find it very, a very, exhausting process - it's like information overload".

"Groups and- Yeah, exactly, as I say, I mean I would attend but obviously would be in- You know, I'd have to, you know, be d-dependant on whether my work, working and that so it might be that I'll be out all day - Yeah, videos and things that's easy accessible would be, um, would be useful as well."

Table 8: Themes, subthemes and codes

Themes	**Subthemes**	**Codes**
1) Difficult mealtimes	1a) Unusual eating habits	Change averse Contamination – food not touching Cutlery use Food jags Forgets to eat or drink Lack of generalisation Needs constant supervision Neophobic reactions to foods Routines and obsessions Secretive eating Sensory problems
	1b) Trying new food is challenging	Reactions to new food: • Anger • Aversion • Escape • Gagging • Panic attack • Paranoia • Refusal • Upset Difficult to take new supplements Spontaneous acceptance of new food
	1c) Eating problems affect children's health, behaviour, learning and mood	Concentration Confusion Constipation Embarrassed Growth Mood and behaviour

Themes	Subthemes	Codes
		Pain Risk Stress Upsetting Urine infections Worried or scared
	1d) Eating problems impact on parents and families	Awful mealtimes Birthday parties Chaotic mealtimes Eating at school Eating out Eats at different times to family Emergencies - Mum in hospital Family occasions Food waste Hidden problem Holidays Impact on occasions Impact on sibling McDonalds Monotonous mealtimes Parental • Boredom • Burden • Desperation • Envy • Exhaustion • Guilt • Sadness • Upset

Themes	Subthemes	Codes
		• Feeling of uselessness • Worry and concern Sits at own table Tense mealtimes Time wasting
2) Unsure when or whether to pursue help		Child will only communicate with parent Don't feel anyone else would be able to help Don't want to be told what to do Doubt that a doctor would take concern seriously Downplaying the problem Eating problems not severe Given up Is it just normal fussy eating? Just muddling through Lowered expectation Naivety Not sought help Not worryingly underweight Prioritisation - eating not the main concern Resigned to it Too busy blaming ourselves Unaware of how to get help Unsure whether to seek help or not
3) Lowered expectations of parents and professionals		Lowered expectation Resigned to it Reduced expectation of dietary quality

Themes	Subthemes	Codes
4) Feeling let down by a lack of support		Advice didn't help Crisis management Doing everything myself Given up Just muddling through Lack of help Long wait to see dietitian Nothing has worked Paediatrician didn't raise concerns Parents requested help Resigned to it Services too stretched to offer help
5) Services must be easily accessible and supportive	5a) The role of school	Help from school Lunchtime observation needed at school Nutrition education needed at school School catering is bad School dietitian school dinner hall modifications School environment needs to be calmer at meal times School food culture School slow to report on not eating at lunch School sports education is good Table manners education at school Whole school healthy eating approach
	5b) A 'super-nanny' service	Help at home One-to-one help
	5c) Group sessions	Drop-in sessions

Themes	Subthemes	Codes
		Difficult to attend appointments Can't attend groups due to childcare Meeting other parents
	6c) Online help	Online help Parent education Self-help guide Any advice is useful Need advice on the bigger picture

5.0 Discussion

5.1 Summary of the results

This study explores the experiences of parents/guardians of children with ASD in Lewisham who have eating problems; the support they have received; and the additional support they would like.

All six participants provided rich and detailed accounts and photographs depicting severe and varied problems associated with their children's eating. Consistent with the literature synthesis the participants' children all had some atypical eating routines and habits, affecting accepted food range and presentation, and all found trying new foods challenging. The impacts on the participants' children varied from challenging distress responses to reduced capacity to learn. The impacts of their children's eating on the families included the direct impact on the mother as stress, anxiety, worry, guilt and time burden, as well as an impact on the whole family's ability to join in social food-related activities.

The participant's children's scores on the validated eating behaviour scales BAMBIC and STEP-CHILD confirmed they all had clinically relevant feeding problems, with varied profiles of difficulties. Moreover, all participant's children had Healthy Eating Index scores below the population average for children, indicating a low dietary quality, with some scores so low due to a lack of variety and lack of inclusion of foods from specific food groups as to pose real risks to health. These findings are consistent with other studies assessing dietary quality in children with ASD via prospective three-day food records (Graf-Myles et al. 2013, Herndon et al. 2009, Hyman et al. 2012)..

Despite these real problems, evidenced by both the quantitative and qualitative data collected, most participants had been unsure whether to seek help, and had accepted that these problems were typical in ASD, and that if their child was growing ok, there was no risk to their health. Additionally, when parents did want help they either did not know where to seek it or felt dismissed by professionals when they did seek help.

Participants report mixed feelings about the support they have received, some feel positive and others feel let down. There is a lack of consensus for what services would be useful. The potential role of schools to offer more support is suggested, with a contrast between the great help experienced in special education provision versus a lack in mainstream provision. Other potential sources of help identified included a one to one home visit 'super-nanny' type service, group sessions, and online support. Barriers to accessing support were identified as inability to attend services due to work commitments and childcare and also the difficulties of physically getting their child to appointments due to their behavioural challenges.

5.2 Interpretation of findings and consistency with other findings

5.2.1 Eating problems in ASD are a significant problem

Eating problems affect up to 90% of children with ASD (Emond et al. 2010). Previous studies have highlighted the range and severity of eating problems in ASD, and this study supports those findings (Johnson et al. 2008, Ledford and Gast 2006, Nadon et al. 2011, Schreck et al. 2004), and highlights parental concern around the impact of their child's eating problems on their wellbeing, behaviour and capacity to learn. Parents describe many ways in which their child's eating problems negatively affect them and their and their families, supporting findings that eating problems can be "one of the most stressful times of the day" (Marquenie et al. 2011).

All children's diet quality scores were below the population mean, some markedly so, moreover, many participants ate no foods from entire food groups. Missing out an entire food group e.g. eating no fruit and vegetables, makes a child at risk of nutrient deficiencies and related health problems (Arimond and Ruel 2004). This sample's dietary quality is of concern as a poor diet in childhood may impact on cognition, behaviour, mental health, academic performance, cardiovascular health (Benton 2008, Florence et al. 2008, Golley et al. 2013, Kohlboeck et al. 2012, O'Neil et al. 2014).

Of note, the amount and richness of discussion provided by parents regarding feeding problems outweighed the amount of discussion regarding services

provided and desired. The problems faced were wide-ranging and caused distress and affected wellbeing in their children and themselves. Full characterisation of the feeding problems was out of the scope of this work but will be teased out and submitted for publication off the back of this study.

This study is the first of its kind to examine parental experience of eating problems in ASD in the UK, and the findings are consistent with the qualitative studies critiqued in the literature review.

In the synthesis of literature (section 2.3) the following themes were identified:

- Theme 1: Mealtimes are horrible

- Theme 2 – Given up on normalcy, caught up in child's idiosyncrasies

- Theme 3 – Lack of support, lack of answers

All three of these themes were echoed in this study, and are discussed in detail below.

5.2.2 Lack of NHS services contribute to parental stress and learned helplessness

Our findings around lack of services and lack of confidence in seeking services resonate with findings in the literature review: In Rogers' study parents reported concerns regarding their child's eating habits being wrongly dismissed by health care professionals as typical toddler fussy eating "when I say he doesn't eat, he doesn't eat" (Rogers et al. 2012). In Suarez's study parents reported that even when they could access support, contact was not regular enough or sustained for long enough to help with change (Suarez et al. 2014).

These findings suggest an aspect of learned helplessness. Learned helplessness theory (reviewed in Liu et al. 2015) postulates that repeated uncontrollable, aversive environmental stimuli gradually leads to the belief that the situation is inescapable and leads to a sense of helplessness, which in turn results in depression. Considering the elevated levels of parenting stress encountered by parents of children with ASD, it is probable that lack of services and lack of support are contributing to stress and depression, which is unacceptable.

5.2.3 Services desired

This study is the first to explore the services desired for feeding problems in children with ASD. Overall the participants did not express strong views on which services they desired. This may be due to some of the issues raised above including a lack of support leading instead to an acceptance of their situation. It was however clear that any support offered would need to be able to fit in with work and care responsibilities. Additionally, noting that what the parents in this study wanted to talk more about was the food problems themselves raised whether there is a need for an outlet for them to talk about their issues and thereby experience some therapeutic benefit and relief for example via group support or talking therapies.

In light of increasingly stretched health systems, stepped-care approaches are increasingly used in order to improve efficiency and best use of resources, (Bower and Gilbody 2005, Carels et al. 2012) whereby patients initially access a first-line step of recognition and self-help, and then move onto more specialist and intensive support if the first-line step has not been sufficient to resolve the presenting problem.

Parent education programmes for the general management of their child's ASD have been shown to improve stress in parents with ASD (Joshi et al. 2013), and challenging behaviours in children (Tonge et al. 2014, Stuttard et al. 2014), and are recommended in the NICE guidelines (National Institute for Health and Care Excellence 2014). Pilots of parent-education strategies for feeding problems in children with and without ASD have been encouraging for parent reported factors (Jones and Bryant-Waugh 2012, Sharp et al. 2014). Digital health interventions (DHIs) such as websites and apps are cost-effective and easily accessible to those who find it difficult to attend face to face appointments (McAuley 2014).

A survey of 2069 adults carried out by Carers UK showed that the use of technology now features regularly in 98% of people's lives, although only 30% report the use of technology to support health and care. For those who were carers (not just for ASD) who did use technology to support caring for their

loved one, 72% said that it had given them greater peace of mind, and over 10% said that it had either helped them to get a job or stay in work alongside caring (Carers UK 2013).

Research into the use of DHIs in ASD has so far only been conducted in Australia for general, not food related aspects of ASD management. The study compared a face-to-face intervention educating parents in general ASD management, with a DHI in 27 parents of children with ASD and found that parent engagement with the DHI, and parent depressive outcomes, were both good and similar to the face-to-face intervention (Ingersoll and Berger 2015).

5.3 Critique of the study

5.3.1 Strengths

This study provides rich insight into the experiences of parents of children with ASD struggling to manage their child's eating problems. The study has been carried out with rigour with care taken to ensure the account is authentic and trustworthy. The findings are consistent with previous findings in related studies.

5.3.2 Homogeneity of the study

The homogeneity of the sample is a study limitation. All participants were mothers in their 40s and most mothers and children were white British. Their experiences may not represent those of the diverse population of families caring for children with ASD. Despite these limitations, the results of the study resonated with previous studies. The rich description of the participants and methods in this report maximise the transferability of the findings.

Collection of further data regarding the participants' educational level, birth order, single parentage and more may have further helped to characterise the sample, and inform transferability due to added thickness of the descriptions of the participants.

5.3.3 Saturation

Saturation is "the point when no new information is obtained from additional qualitative data" (Morse 1995). This point of sufficient data collection in turn

informs sufficient sample recruitment and therefore the sample size. However, the judgement of when saturation has occurred is subjective (Fusch and Ness 2015, Kerr et al. 2010). Data saturation is best achieved by collecting rich (quality) and thick (quantity) data (e.g. via interviews, or focus groups) and strengthened via triangulation. The sample size of this study was relatively small (six mothers), however several factors suggest saturation was achieved: the data collected was rich, including in-depth interviews and participatory photography; the sample was relatively homogenous, and findings were aligned with previously published research.

The inclusion of tools quantitatively characterising the children's' behaviour, eating problems and dietary quality (CAST, BAMBIC, STEP-CHILD and HEI-2101) was in order to confirm eligibility and stratify into group if sample size had allowed, rather than for any further analysis, however a larger sample size may have allowed for more quantitative analysis of these results.

5.3.4 Use of Computer Assisted Qualitative Data Analysis (CAQDAS)

CAQDAS software such as NVivo, used in this study, are established tools to aid organising, managing and analysing qualitative data (Banner and Albarrran 2009). As well as saving time, CAQDAS tools enable increased transparency and rigour in data analysis via the easy generation of audit trails. However the use of software can reduce the flexibility of analysis and distance the researcher from the data (St John and Johnson 2000). Care was taken to ensure that the use of NVivo did not in any way constrain data analysis by journaling and supervisory discussions.

5.3.5 Novice researcher

Angen argues that the credibility of research rests on the skills and competence of the researcher (Angen 2000). The author's inexperience as a novice researcher was unavoidable, and may have affected the quality of data collection, and data analysis. This was mitigated against using triangulation: the involvement of an experienced supervisory team, member-checking and the use of participatory photography as additional data sources. It was not however possible to include investigator triangulation in data collection, and the quality of

the interview data relies on the interviewer interacting with participants in a skilled way in which to "generate rich and complex insights" (Braun and Clarke 2006). Although some of the communication skills used in the author's clinical work cross over to those needed in skillful interviewing: being friendly and open, using active and attentive listening and building fast rapport and trust, this does not substitute for research experience.

5.3.6 Inclusion and exclusion criteria

Participant 6's views on support were polarized to that of the other participants – having had an overwhelmingly positive experience. It may be assumed that participants with longstanding feeding support needs such as their child previously being tube fed (as was this participant's experience), would have a very different experience, but equally may have more insight due to having had more engagement with services. Potentially a more specific inclusion and exclusion criteria could have excluded this participant however if a larger sample had been recruited this participant may have been stratified into a similar group. The value in including this participant's views may add to the existing data in highlighting that negative experiences of feeding support are not universal in Lewisham. The seeking out and examination of deviant views is often seen as a positive in qualitative research, adding to rich insight and methodological rigour (Anderson 2010).

5.4 Clinical implication of results

This study has highlighted and reiterated three key issues which could have clinical implications for professionals:

1) Parents with children with ASD and feeding problems in Lewisham are unsure when or whether to seek help
2) Parents and professionals are often dismissive of eating problems which impact on dietary quality (and therefore on health)
3) When parents do seek help, there are gaps in services

This study reinforces the need for more support for parents of children with ASD and more support directly for children with ASD to manage their eating

problems. These findings may be transferable to other areas of the UK where health services for children with ASD are patchy.

It is well established that a good quality diet is key to both mental and physical health, indeed it is leading modifiable factor in disability adjusted life years in the general population (Newton et al. 2015). Dietary improvement is both a global and national public health priority (Public Health England 2017, 2016, Were et al. 2015,World Health Organisation 2004).

The finding that professionals are sometimes dismissive of eating problems in ASD is problematic because, as discussed in the previous section, eating problems impact on a child's dietary quality, health, wellbeing, learning and behaviour, and cause a lot of stress for parents and families. Moreover, in cases of severe restriction, nutritional deficiencies can result and ultimately can result in death, independent of weight status. The author regularly comes across professionals who feel that children with ASD thrive despite very imbalanced diets, and has heard this opinion shared in national talks and even amongst dietitians. UK law protects against discrimination under the Equality Act (Equality Act 2010, 2013), with particular duties for all public services including the NHS. Direct discrimination is defined as "where the reason for a person being treated less favourably than another is a protected characteristic … such as a mental or physical disability… The person is protected both when requesting a service and during the course of being provided with a service." (Equality Act 2010, 2013). It seems impossible to argue that applying a different threshold for adequate diet to children with ASD versus the general population (without a justifiable reason) is not direct discrimination. The reason for and extent of the lowered expectations in professionals warrants further exploration.

5.5 Moving forward

This research has highlighted the gaps in provision in this clinical area. In disseminating this research, the gaps in provision and the possible culture of dismissal of eating problems in this sample are being highlighted to local teams and commissioners. Details of dissemination activities are included in the

Clinical Research Portfolio submitted as an accompanying artefact for this award. Evaluation of the views of other stakeholders including commissioners and other professionals in Lewisham is warranted.

The following questions warrant further investigation:

- What impact do eating problems in children with ASD have on their physical and mental health, behaviour and ability to learn?
- What is the extent of and the reasons for lowered expectations in health professionals of dietary intake and quality in children with ASD?
- Is the dietary quality of children and adults with ASD lower than that of the general population? To what extent does this contribute to the lowered life expectancy in ASD?

What approaches can be employed in a cost-effective way to help parents of children with ASD in Lewisham?

Previous discussions with stakeholders as part of the author's interdisciplinary team have identified the need for first line digital health intervention as a cost effective and easily accessed addition to the care pathway. The results of this study show that some participants would find online support acceptable whilst one participant would not.

Next steps will include a quantitative systematic literature review of intervention effectiveness in this field plus qualitative research seeking professionals' and commissioners' views of what services are required to improve outcomes.

The author has prepared an application for further NIHR funding for a follow-on study as a PhD: the development and feasibility testing of a digital health intervention to help parents of children with ASD identify and manage their feeding problems. The development of the research topic included patient and public involvement (PPI) (Hayes et al. 2012). The application and methodology are further discussed and included in the Clinical Research Portfolio, and would include co-design of the intervention in conjunction with the identified local stakeholders.

6.0 Conclusion

In summary, this research successfully examined the experiences of parents/guardians of children with ASD in Lewisham who have eating problems; the support they have received; and the additional support they desire.

In a sample of six mothers of seven children with ASD, it was found that mealtimes are difficult, and impact on both the child's and parent's health and wellbeing. These findings are the first of their kind in the UK and concur with other published findings.

This study further revealed that parents are unsure when or whether to pursue help and feel let down by a lack of support; professionals have lowered expectations of children with ASD's eating habits and dietary intake; and desired services must be easily accessible and supportive. The findings of this study are important as eating problems have a significant impact on children with ASD and their families.

These results highlight the need for increased awareness and understanding of eating problems amongst health professionals; improved and more accessible services to help parents of children with ASD manage their children's eating problems.

Exploring eating problems, services offered and desired has been key in identifying priorities for service development and research. Future research will focus on the feasibility testing of a digital health intervention to help parents of children with ASD identify and manage their eating problems.

This research has uncovered some key issues that can be addressed to achieve the secondary aim of aiding the plan of better services and multi-disciplinary support for the future to improve the wellbeing of children with ASD their families in Lewisham, and countrywide.

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Appendices

Appendix 1: Draft manuscript: Severe nutrient deficiencies in autism spectrum disorder – a systematic review of published cases

Abstract

Background: Children with autism spectrum disorder (ASD) have a 5 times higher prevalence of feeding problems than typically developing peers and as a result are at an increased risk of nutrient deficiencies which can have life threatening or life changing consequences. **Objectives**: To conduct a systematic review of case reports identifying nutrient deficiencies in ASD **Data sources:** The databases Medline, EMBASE, Web of Science, PubMed ePubs and Cochrane CENTRAL were searched, with no restriction through October 2017 **Study Selection:** Studies reporting cases of nutrient deficiencies (? And overloads) in individuals with ASD were included **Data Extraction:** Data was extracted on patient characteristics, presenting problems, diagnosis, management and outcomes **Data synthesis:** x publications met inclusion criteria, reporting on x 37 cases. All involved children in resource-rich countries. The most frequently reported nutrient deficiencies were of vitamin C deficiency (scurvy) (20) of which 11 presented with limb pain and walking difficulties; all cases resolved quickly with vitamin C supplementation. 7 cases were of vitamin A deficiency all of which presented as visual difficulties and were only partially reversible with supplementation. The remaining 10 covered hypomagnesaemia, vitamin B12, iron, zinc or multiple deficiencies. 28 of the 30 cases were due to the extreme food selectivity that is common in ASD. **Limitations**: This study is limited by information available in the original reports. **Conclusions**: Evidence from case reports shows that children with ASD are at risk of sometimes irreversible harm from restricted diets resulting from rigid eating habits. Deficiencies are preventable and children with ASD should be screened for feeding problems and dietary adequacy. Dietitians have a key role in assessing for dietary inadequacies and advising on and supporting changes to prevent the onset of severe deficiencies and promote a balanced diet for optimal health and wellbeing as part of the multi-disciplinary team.

Introduction:

Autism spectrum disorder (ASD) is a lifelong developmental disorder characterised by impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours. ASD is typically diagnosed in early childhood and affects at least 1 in 100 children in the UK (1).

Individuals with ASD often have many co-existing mental and physical health problems. On average adults with ASD without a learning disability die 16 years earlier than the general population, and adults with ASD and learning disabilities die 30 years earlier. Mortality rates from all causes, including those related to nutrition, are more than doubled (2–4). 74% of people with ASD and their carers in the UK feel they receive 'worse' or 'much worse' healthcare than the general population, and 65% think that health professionals have poor understanding of how ASD affects health (5). Under-reporting of mental and physical health problems by individuals and their carers, and diagnostic overshadowing are barriers that need to be overcome to provide more adequate health care (5).

Eating, drinking and nutritional problems are common in ASD. Feeding problems such as extremely fussy eating are 5 times more common in ASD than in typically developing children, affecting up to 90% of children (6–8). Eating habits can be extremely rigid e.g. only eating 2 or 3 foods, preference for food that is only 'dry' or 'wet', a particular colour or shape or from a specific brand packaging (7). Food hypersensitivities, gastrointestinal problems and disordered gut microbiota are more common in children with ASD (9–14). Sensory processing difficulties, oro-motor discoordination and challenging eating behaviours are other contributing causes of feeding problems (7,15–17). Although it is unclear whether rates of underweight, overweight and obesity are higher than or comparable to rates in the general population (18–26), children with ASD are significantly more likely to be at risk for developing nutrient deficiencies (27), have a significantly lower consumption of calcium, protein, and vitamins B12 and D (27–29), and a third have intakes below the Lower Reference Nutrient Intake (LRNI) for iron, zinc, calcium, and vitamins A, B2, and B12 (7). Bone mineral density of young children with ASD is significantly lower than the reference for their age (30). Serum 25-hydroxyvitamin D levels are significantly lower in children with ASD than peers (31); rates of iron deficiency range from 8-24% (32–34); and biochemical markers of biotin, folate, and vitamins B5, B12 and E are lower in children with ASD versus controls (35). Prevalence of other deficiencies are not known. Omega 3s? Therapeutic doses of vitamins? Therapeutic diets? Nutrition is also linked to possible contributory causes to ASD or ASD related comorbidities(36) Also China study Liu (37) and other new study Castro (38)

There is a lack of high quality evidence or consensus as to the effective management of feeding problems in ASD. The NICE guidelines for the management of ASD in under 19s highlight feeding problems as a common coexisting problem but make no recommendations for assessment or

management, and no mention of dietitians (39). Registered dietitians play key roles in assessment and management of nutritional, dietary and feeding problems and are the only professionals trained to assess an individual's diet for micronutrient adequacy and therefore provide early identification of and prevention of nutrient deficiencies (40,41). Impact of eating problems on parents?

In light of the high prevalence of nutritional and feeding problems in ASD, this review collates published cases of severe nutrient deficiencies in ASD for the first time. The aim is to identify any common features of these cases, for example patterns in presentation, which could serve as 'red flags' to physicians and dietitians.

Methods:

Data sources and searches

Searches were carried out in x databases: Medline, EMBASE, Web of Science, PubMed ePubs, PsychInfo, AMED, Cochrane Library-CENTRAL, Cinahl and Academic Search Complete, with no restrictions, up to October 2017. Manual bibliography search of the selected articles was also performed. The search strategy is provided in Appendix 1.

Study selection

Screening of eligible publications was carried out by the primary author. First by screening titles and abstracts and then by reviewing the full text of likely relevant articles. Consideration was given to exclusion of papers which did not detail verification of autism spectrum diagnosis; however this would have excluded most papers therefore all papers were included if they stated that subjects had ASD or a diagnosis which has previously fallen under the ASD umbrella e.g. autism, Asperger syndrome or pervasive developmental disorder not otherwise specified (PDD-NOS).

Data extraction

Data was extracted by the primary author. (For articles published in languages other than English data was extracted using Google translator.?). Data extracted included: patient characteristics (demographics, reported diagnosis), presenting complaint, how deficiency or overload was established, and …..

Quality assessment

Results:

Search Results

743 de-duplicated papers were identified from the search strategy, 624 were excluded as irrelevant from their title and abstract? Etc etc The search yielded 30 papers out of a potential pool of 743 (Figure 5). Two (6%) were published from 1993-99, seven (28%) from 2000 to 2009 and 16 (65%) since 2010.

The 25 papers contained 30 case reports of severe nutrient deficiencies in ASD. Two thirds of reports (20 reports) were from the USA. Only one of the 30 cases were female. No cases in adulthood were identified; the age range of cases was 2-17 years old (mean 8.5 years old, median 9 years old) (see

PRISMA 2009 **Flow Diagram**

Table 9 for details of location age and deficiencies in the case reports).

Figure 5: Flow diagram of included and excluded studies

PRISMA 2009 Flow Diagram

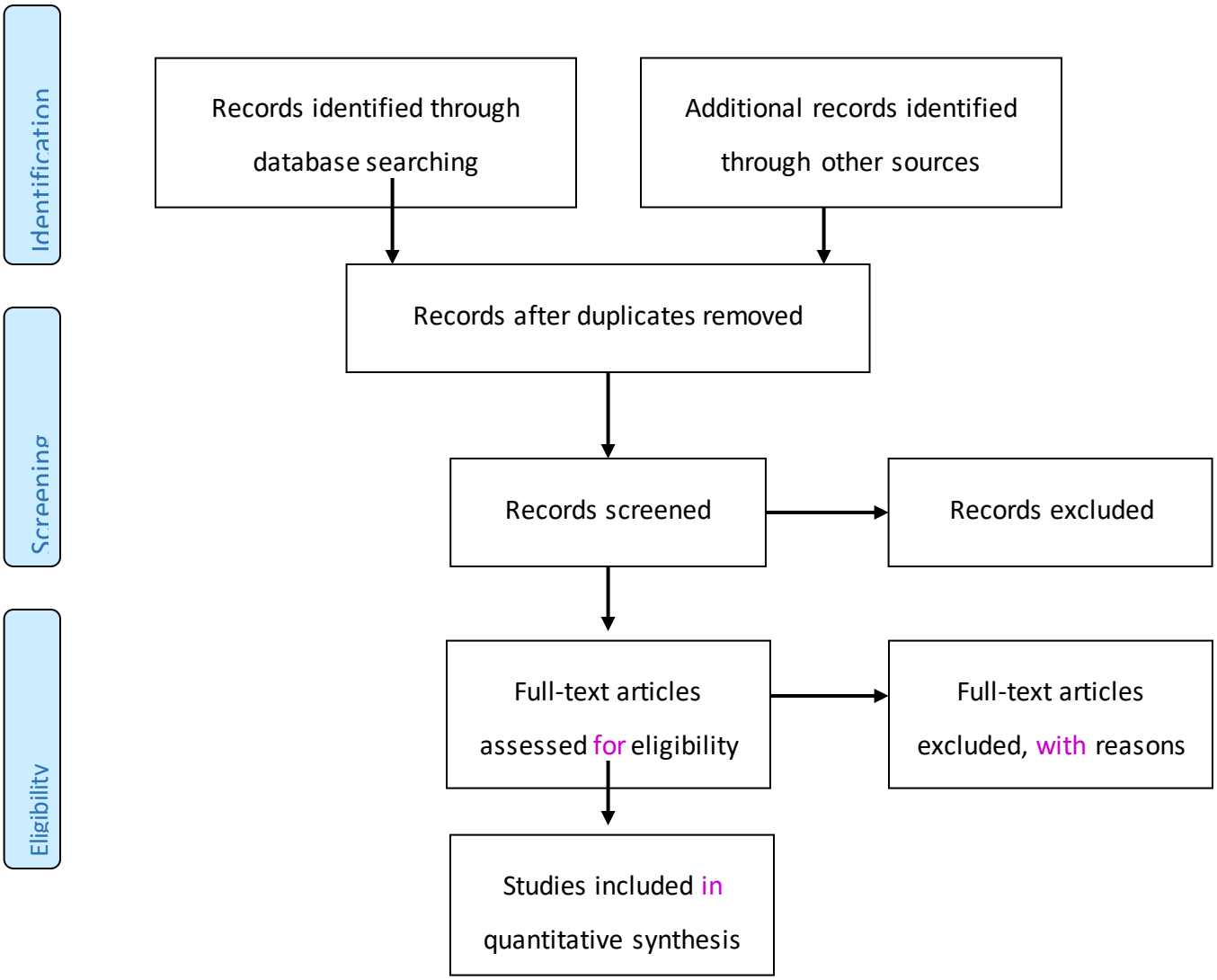

Table 9: Details of 37 case reports

Details of case reports		**No of subjects**
Country of first author	USA	27
	Ireland	2
	Japan	2
	UK	1
	Turkey	1
	New Zealand	1
	Italy	1
	Germany	1
	Australia	1
Age range of subject in years	2-4	4
	5-7	8
	8-10	12
	11-13	6
	14-17	3
	Missing	4
Gender of subject	Male	31
	Female	2
	Missing	4
Date of publication	1995-99	2

	2000-04	2
	2005-09	6
	2010-13	14
	2014-16	13
Deficiency	Vitamin C	20
	Vitamin A	10
	Vitamin D	8
	Protein/energy	3
	Vitamin B_{12}	2
	Vitamin B_1	2
	Vitamin B_6	2
	Iron	2
	Zinc	2
	Folate	1
	Magnesium	1
	Multiple	9

Characteristics of included studies

Table 10 lists the details of data extracted from the 37 identified cases on the clinical presentation of the case, the diet and the treatment.

Two thirds of reports (20 reports) were from the USA. Only one of the 30 cases were female. No cases in adulthood were identified - the age range of cases was 2 – 17 years old (mean 8.5 years old, median 9 years old). Diagnoses of deficiencies were made via clinical assessments alongside biochemical and radiological assessment where necessary. Positive response to micronutrient supplementation confirmed the diagnoses.

The most common micronutrient deficiency identified by these case studies was vitamin C, there were 13 cases of scurvy. It is of note that all presented with problems or pain on walking and this was the key issue in 11/13 rather than the classic symptoms of rash or gingival bleeding, which were often present but had been previously overlooked. All of these cases reported a speedy (within 24 hours) symptom improvement on initiating vitamin C supplementation.

There were 7 cases of vitamin A deficiency, with visual impairment being the presenting symptom – sometimes accompanied by mobility problems – due to disorientation due to loss of sight. Vitamin A supplementation only partially reversed visual impairment in many of the cases which reported on outcomes, with some cases experiencing life changing visual impairments e.g. the inability to be able to read (42).

One case of severe weight loss and deficiencies was caused by phytobezoar caused by pica and intake of plant materials (43). One case of hypomagnesaemia was caused by parental application of a restricted diet and twice daily water enemas as an alternative therapy for their child's ASD (44). The remainder of cases were reported to be caused by self-limiting diets (i.e. extreme food selectivity) which sometimes consisted of only one food e.g. fried chicken (45). The majority of cases were not underweight for age.

Table 10: Details extracted from publications on presentation, clinical details, treatment, outcome and dietary details, critical appraisal score

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Magnesium (44)	4, m, New Zealand, ASD	'Restricted diet' plus twice daily water enemas for 'some months'	P: Intermittent episodes of muscle spasm in his hands and feet (carpodedal spasm) for several months. C: serum Mg 0.17mmol/l (0.7-1.1), adjusted Ca 1.57mmol/l (2.15-2.55), K 2.5mmol/l (3.5-5.2), normal ECG. T: intravenous electrolytes O: serum Mg stable, symptoms resolved
Protein/energy (47)	10, f, USA	'Only ate certain types and brands of foods'. Gradual reduction of range and intake over 4 months	P: Severe malnutrition and weight loss over 4 months progressing to severe constipation and encopresis T: nasogastric feeding due to refusal to eat. Behaviour modification plan. O: refusal continued, weight gain improved with tube feeds. Trigger identified to be stress due to changing school. Modified behaviour management saw improvement in eating.
Protein/energy and zinc (47)	3, m, USA, autism	Commercial pureed fruit and coconut juice only for 2 years	P: Lethargy and generalised non-pitting oedema for 6 weeks C: Erythematous, scaly rash, coarse thin hair, anaemia, hypoalbuminaemia, hypoproteinaemia. Diagnosed with kwashiorkor. T: nasogastric feeding, zinc supplementation, referral to inpatient feeding disorders unit. O: weight gain, resolution of rash.

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin A (48)	8, m, Turkey, autism and epilepsy	Only fried potatoes and water for 4 years	P: Progressive visual impairment. C: serum vitamin A 10ug/l (360-1200). Diagnosed xerophthalmia T: intramuscular vitamin A (100 000 IU) then oral supplementation. O: partial regain of sight, reduced agitation
Vitamin A (49)	5, m, USA, severe autism	Mostly bacon and KoolAid, occasional blueberry muffins. Refused vitamin A supplements.	P: corneal ulceration, red and sore eyes and light sensitivity. C: diagnosed xerophthalmia, serum vitamin A <50ug/l (360-1200) T: 100,000 IU vitamin A intramuscularly, repeated 2 months later. O: Symptoms resolved
Vitamin A (50)	17, m, USA, moderate to severe autism	Potato chips (crisps in UK English), pretzels, snack mix, cookies, and seltzer water. Intake of 10IU per day vitamin A (<1% US recommended daily allowance of 3000IU)	P: Vision loss over 5 months C: serum vitamin A levels <2ug/dl (26-72), weight-for-height 10-25%, height-for-age 50% T: 200 000 ID/d vitamin A intramuscularly for 2 days then dietetic help and nutritionally complete sip feed given (and accepted) 4 x per day to provide 40% recommended daily allowance of vitamin A. O: partial regain of sight, weight and agitation improved

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin A (51)	10, m, USA, moderately severe autism, well controlled seizure disorder	'picky eater - potatoes and a few other items'	P: Dry and sore eyes, red eyes for several weeks, didn't improve after erthyromycin ointment qds. C: Diagnosed with idiopathic intercranial hypertension 4 months previous after presenting with headaches. Mild papilledema in both eyes, reduced visual acuity, serum vitamin A <3ug/dl (20-120), diagnosed with vitamin A deficienc and xerophthamlmia. T: oral vitamin A supplementation, topical all-trans-retinoic acid ointment. O: eye symptoms resolved at 6 weeks
Vitamin A	11, m, USA, autism	6 month history (since having chicken pox) of only French fries, chicken strips, apples. Refused all vitamin supplementation.	P: one-month history of worsening fatigue, severe photophobia, eye pain, conjunctival injection and eye rubbing. Eye symptoms had not improved on Tobradex eye drops. C: visual impairment, blood-free retinol level <20ug/l (360-1200) T: Vitamin A supplementation 100 000 USP units of vitamin A palmitate intramuscularly, plus supplements of zinc, magnesium, vitamin B12 and B-complex O: 2 weeks later free retinol increased to 333ug/l and all symptoms resolved.
Vitamin A (52)	9,m, USA, autistic	Only French fries	P: visual loss and red eyes over 4 months C: serum vitamin A 3ug/dl (39-98) T: oral vitamin A supplementation O: resolution of symptoms

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin A and D (53)	8, m, USA	French fried potatoes and water for past 2 years. Refusal of multivitamins and other foods	P: Limp, periorbital swelling, xerophthalmia and corneal erosions C: hypocalcaemia, radiographic evidence of rickets, serum vitamin A undetectable (<0.35umol/l), serum vitamin D 15nmol/l (25-137), serum total calcium 1.52mmol/l (2.20-2.58), vitamin E, B12, folate, zinc, ferritin normal T: Nasogastric feeds of Pediasure, 50000 units of vitamin A for 7 days, then reduced to 5000units/d, referred for intensive psychotherapy O: all biochemical abnormalities reversed, eyes improved within a week, rickets healed radiographically by 10 weeks. 3 month refusal of all oral intake resulted in ongoing nasogastric feeding.
Vitamin A and D (54)	14, m, Ireland, ASD	Almost entirely bread and fried potatoes	P: decreased vision for 5 days, rash on upper limbs for 10 weeks C: Bitot's spots in eye, serum vitamin A undetectable, vitamin D insufficient (32ng/ml, vitamin B12 borderline (150pg/ml). T: 25000 IU/d vitamin A orally daily and attempt to increase dietary intake. O: improved vision, school performance and alertness
Vitamin A and D (54)	13, m, Ireland, moderate ASD	'severely restricted'	P: 6-week history of decreased vision and deteriorating alertness C: serum vitamin A undetectable, vitamin D <15ng/ml T: oral vitamin supplementation O: complete resolution of symptoms within a week

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin A and D, folate, iron (55)	5, m, USA, autism	Fried potatoes, rice balls and water for 2 years	P: Dry eyes C: serum vitamin A undetectable, serum folate 3ng/ml (5-21), vitamin D <5ng/ml (7-41), Hb 11.3g/dl, diagnosed with Xerophthalmia T: 1500ug/kg body weight vitamin A for 5 days. O: symptoms resolved
Vitamin B1, B6, and A (45)	11, m, USA, autism, developmental delay	Mainly fried chicken nuggets for several years. Occasional French Fries and bites of bagel.	P: Skin abscess, reduced alertness. C: hepatomegaly, liver dysfunction and severe lactic acidosis, bilateral optic neuropathy, defects in mitochondrial function, serum vitamin A <0.06mg/l (0.2-0.5), serum vitamin B6 7.6ng/ml (20-125), copper 55ug/dl (90-120) T: parenteral vitamin B1, K and 'other micronutrients' supplementation O: improved lactic acidosis within hours, normalisation of mitochondrial function. P: 2 weeks later - status epilepticulus T: 100mg parenteral vitamin B6 O: resolved. Discharged home after 1 month on nasogastric feeds, gastrostomy tube placed 2 months later then lost to follow up

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin B12 & A (56)	6, m, USA, autistic	Primarily bagels, cereal and French fries, no meat	P: 1-month history of decreased visual acuity C: Brain MRI normal, Lyme titers normal, ESR normal, vitamin B12 level <150pg/ml (245-1078), methylmalonic acid 1781umol/l (145-345), haemoglobin normal, vitamin A 14pg/ml (26-72), no GI cause for deficiencies T: intramuscular vitamin B12 O: normalisation of vision and blood levels (note no treatment of monitoring in vitamin A noted)
Vitamin B12 (56)	13, m, USA, autistic	Mainly potatoes, fruit, bagels	P: gradual vision loss over 6 months C: bilateral optic atrophy, previous history (5 years ago) of low vitaimns A and B12 treated with IM B12. Blood tests 3 months previous = vitamin B12 297pg/ml, vitamin A 2pg/ml; brain MRI normal, blood tests B12 195pg/l, MMA 2082 umol/l, vitamin A 61pg/ml (normal), no GI cause for deficiencies, mild anaemia. T: vitamin B12 O: normalisation of bloods and vision
Vitamin B12 (56)	7, m, USA, autistic	Primarily French fries and occasionally processed chicken nuggets.	P: 6-week history of changing visual behaviour. C: bilateral optic atrophy, MRI – normal, lumbar puncture normal, vitamin B12 155pg/ml, MMA 512 umol/l. Vitamin A normal, no GI cause for deficiencies. T:vitamin B12 injections O: blood levels and vision normalised.

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin C (57)	9, m, USA, autism	'Decrease in appetite'. Further details from (58): peanut butter and marshmallow fluff sandwiches, cheese pizza, McDonalds chicken nuggets, Ritz crackers and various chocolate biscuits, water; no milk, fruit or vegetables	P: Pain in the hip, refusal to walk, rash, lethargy, irritability, appetite and weight loss Problems started 3m prior after upper respiratory illness C: gingival swelling, serum vitamin C <0.12mg/dl (normal range 0.2-1.9), serum 25-hydroxyvitamin D 13ng/ml (normal range 20-100) T: oral vitamin C 160mg daily plus a multivitamin O: Able to walk and appearing more comfortable within 24 hours, continued improvement over a month.

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin C (58)	4, m, USA, autism	'long standing avoidance of fruits, vegetables and Vitamin-C fortified foods'. Brazilian cheese bread, rice, beans, chocolate chip cookies, chicken nuggets, ground beef, original Capri-sun, no milk, fruits, vegetables	P: limp for 1 month, fatigue, abdominal pain, decreased appetite and weight loss C: MRI showed subtle changes in metaphysis and oedema in soft tissues of knees. T: 60mg/d vitamin C and drinking 20oz/d cashew fruit juice (60mg vitamin C) O: resolution of symptoms after 4 days, vitamin C level 1.4mg/l after 1 month

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin C (58)	11, m, USA, autism	Dietary analysis – intake is 3% of RDA for vitamin C. Potato bread, blueberry muffins, snack cakes, Sun Chips, chicken nuggets, turkey lunch meat, ketchup, peanut butter, water, no milk, juice, fruits or vegetables.	P: 2-week history of knee pain, limp and refusal to walk, mild swelling and bruising along thigh and tibia. C: MRI patchy epiphyseal signal. Serum vitamin C 0.2mg/l. diagnosis of scurvy due to diet history. Deficiencies of vitamin A, B6, C, D, calcium, folate, iron T: multiple vitamin supplements and vitamin C fortified juice to provide a total of 506mg/d vitamin C O: at follow up 2 months later all symptoms resolved.
Vitamin C (58)	11, m, USA, autism	Cereal, rice, pasta, steak and potatoes (slow cooked), toast, cheese, milk: no juice, fruits, vegetables	P: limp for a few weeks, unable to bear weight, decreased appetite, swollen gums, ecchymosis over left knee. C: MRI symmetric marrow oedema and metaphyseal enhancement at distal femurs, proximal tibias and fibulas. Serum vitamin C <5umol/l, zinc deficiency, diagnosed with scurvy. T: vitamin C and multivitamin O: immediate improvements in appetite and gum swelling, gait improved within 6 days, returned to baseline activity at14 days. Serum vitamin C at 10 days 13umol/l

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin C (59)	11, f, USA, autistic disorder	Peanut butter and apple jelly (UK English = jam) sandwiches, cereal bars, milk, strawberry-kiwi drink, chocolate pudding, yogurt. 'Intake estimated at 10-20% of recommended daily allowance of vitamin C'. long standing refusal to take supplements due to aversion.	P: Acute loss of ambulation over course of one day. C: fever, vomiting, general weakness, knee swelling, bruising on legs and gingival hyperplasia, serum vitamin D zero (0.4-2.0 mg/dl). Diagnosed with scurvy T: 300mg/d vitamin C plus daily multivitamin, referral to feeding team O: symptoms began to resolve within days
Vitamin C (60)	2, m, Italy *NB subject had 'autistic behaviours' but not clear if had diagnosis of ASD	Only milk	P: Severe muscle weakness and pain in lower limbs C: gingival bleeding T: 'diet supplement containing vitamin C' O: 'rapid and dramatic clinical improvement' – positive mood, resolution of gingival bleeding, disappearance of limb pain, restoration of ambulation.

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin C (61)	10, m, USA, autism, trisomy 21	3-year history of diet limited to: peanut butter and jelly (jam in UK English) sandwiches, soya bacon, pasta, waffles, wheat porridge, cheese crackers, vanilla pudding, toaster pastries, chocolate sandwich cookies, and pretzels.	P: Rash (petechaie), easy bruising and bleeding and walking with a limp. C: serum vitamin C <0.12mg/dl (0.2-1.9) T: vitamin C supplementation O: symptoms resolved within 3 days
Vitamin C (62)	7, m, USA, autistic, severe compulsive traits	Macaroni cheese, pizza, chicken nuggets, pudding pops, Doritos, water and Dr Pepper	P: Limping for 3 years, nose and gum bleeding, weakness, bone pain, fatigue and behavioural changes, weight loss, sacral, abdominal and scrotal swelling, rash on lower extremities, arms and chest, unable to support own weight C: Diagnosed with muscle atrophy and scurvy T & O: not stated

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin C (63)	10, m, USA, autism, slight developmental delay	Hamburgers, Wheat Chex, Pop Tarts, oyster crackers, and pancakes.	P: Muscle atrophy, hypertrophic, bleeding gingiva, leg bruising. C: punch biopsy of the ecchymotic area of his leg revealed perifollicular haemorrhaging, serum vitamin C <0.12mg/dl (normal range 0.2-1.9) T: oral vitamin C 100mg bd and multivitamin following dietetic input O: clinical improvement within 24 hours, normalisation of serum levels and all symptoms resolved
Vitamin C (64)	5, m, USA, autistic disorder	Almost exclusively chocolate milk for 4 months	P: Abnormal gait, progressive back and leg pain, and swollen wrists C: serum vitamin C <0.1mg/dl (0.6-2.0) T: 'repletion' O: clinical improvement
Vitamin C (65)	6, m, Japan, autism and 'mental retardation'	'extremely unbalanced diet'	P: Difficulty walking. 6-month history of fever, petechaie and worsening limping C: gingival hyperplasia and bleeding, muscle atrophy, anaemia, serum folic acid <1.2ng/ml, serum vitamin B_{12} 137pg/ml. T: vitamin B12 and folic acid and discharged Next day: P: thigh swelling C: serum vitamin C <0.2mg/l (5.5-16.8), diagnosed with scurvy T: vitamin C O: symptoms reduced in several days

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin C (66)	9, m, Germany, autistic behaviour, cerebral palsy and global delay	'highly limited food range': low fat milks, commercial drinking milks, vanilla and chocolate puddings only for 4 months.	P: Bruising and refusal to walk since fall 2 weeks before C: Petechiae, gum bleeding, leg pain, anaemia, impaired platelet aggregation, serum vitamin C 1.0mg/l (4-20) normal vitamins A, B12, E, D, K, ferritin, copper and zinc T: 250mg/d vitamin C O: Rapid improvement of mood, irritability resolved within 3 days, vitamin C level of 14mg/l and platelet aggregation normal 3 weeks later
Vitamin C (67)	9, m, USA, autism	Oatmeal and soya milk only 'due to sensory aversions'	P: Refusal to bear weight, draining mouth sore, swollen knee. C: serum vitamin C level undetectable T: oral vitamin C 500mg od, speech therapy input to widen food range. O: gingivitis, energy level and mobility quickly improved. Serum vitamin C level normal 4 weeks later.
Vitamin C (68)	7, m, USA, Asperger syndrome and developmental delay	Yogurt only	P: Lower extremity pain, inability to bear weight, gingival hyperplasia, easy bruising, hyperkeratosis of upper and lower extremities, intermittent swelling of joints. C: serum vitamin C zero, raised CRP. T: 'change of diet' O: decreased pain and improved mobility

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin C (68)	6, m, USA, autistic	Sugar-sweetened breakfast cereal, ice cream, and crackers.	P: Diffuse bone pain and refusal to walk. Gingival bleeding. C: serum vitamin C zero T: vitamin C O: resolution of symptoms
Vitamin C (68)	8, m, USA, autism, asthma and anemia	Spaghetti, meatballs, and potato chips (crisps in UK English).	P: 3-week history of hip, knee and ankle pain. 3-day history of rash on legs, sore on mouth, bleeding gums. C: serum vitamin A and D low, serum vitamin C 'unable to be ascertained' MRI confirmed scurvy T: vitamin C supplementation O: marked clinical improvement

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin C and D Noble 2007 (69)	???_The North American epidemic of overeating, combined with a sedentary lifestyle, has led to a growing prevalence of obesity, diabetes, and the "metabolic syndrome" in children.	??? Excessive caloric intake does not imply adequate nutrition, and vitamin-deficiency syndromes still occur in some American children. Here we describe cases of scurvy and vitamin D deficiency in 2 children with cognitive disorders.	??? Thorough dietary histories suggested the diagnosis in each patient and, had they been obtained at presentation, would likely have obviated invasive diagnostic workup, unnecessary stress to the patients and their families, and significant functional disability. Overnutrition and malnutrition may coexist,particularly among those with abnormal cognition or autistic spectrum disorders. Classic nutritional deficiencies must not be omitted from the differential diagnosis. A comprehensive dietary history and screening for vitamin deficiencies in at-risk children are important aspects of preventive health care and are essential for prompt diagnosis and treatment.
Vitamin C, D, iron, zinc and protein/energy (43)	11, m, Australia, autism	Pica, often ate grass and cigarette butts and sometimes balloons.	P: 2-month history of increasing agitation and self-injurious behaviour, decreasing oral intake and weight loss, gagging and decreased frequency of bowel actions. C: Laparotomy, found a large phytobezoar (trapped indigestible plant matter in gut). Deficiencies in iron, vitamin C, vitamin D and zinc identified. T: surgical removal of bezoar, parenteral nutrition. O: return to normal health within 6 weeks

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin C and D (70)	5, m, USA, autism, developmental delay	Taquitos, frozen pizza rolls, the crust of fish sticks, nacho cheese snacks and water	P: Hip pain and difficulty walking. C: X-ray showed osteopenia Serum 25-hydroxyvitamin D 16ng/ml, serum vitamin C <0.1mg/dl T: started on vitamin D but then lost to follow up. Same case 5 months later: P: refusal to walk, weight loss (50th centile to <3rd centile). C: serum vitamins D, B12, B1 and folate, calcium, magnesium normal, serum vitamin C <0.1mg/dl. Bone density scan and x-ray showed osteoporosis. T: 'vitamin C replacement' O: ability to walk after 2 weeks. After 6 months despite dietetic and speech therapy still refusing fruits and vegetables.

Nutrient deficiency and reference	**Age in years, gender (m or f), location, diagnosis**	**Dietary details**	**Presentation (P), Clinical details (C), Treatment (T), Outcome (O)** clinical results reference/normal ranges in brackets
Vitamin C, B1, B6, B12 and D (71)	9, m, USA, ASD	Mainly white foods, including chicken nuggets, crackers, cookies, and water for 3 years. No milk or fruit and vegetables or supplements.	P: dry cough, laboured breathing, 4-month history of limp, progressed to unable to walk, slight bleeding gums C: pulmonary hypertension and heart failure (suspected cardiac beriberi), serum vitamin C undetectable, vitamin B1 55nmol/l (70-180), vitamin B6 3.5ng/ml (5-30), vitamin B12 <120pg/ml (190-778), 25-OH-D 8.2ng/ml (30-80), vitamins A, B2, B3, E, selenium, zinc and folate normal. T: Intravenous ascorbic acid, thiamine, ergocaliferol and multivitamins plus intramuscular vitamin B12 followed by oral supplements on discharge O: Resolution of respiratory symptoms in 10 days, and all other symptoms in 3 weeks.
Vitamin D (72)	15, m, UK, ASD	'Poor since infancy'. Mainly chips and gravy, minimal exposure to sunlight.	P: Bilateral leg pain and weakness, tiredness. C: pale, below 0.3rd centile for weight and height. Serum 25-hydroxy-vitamin D undetectable, low corrected calcium, raised alkaline phosphatase, raised parathyroid hormone. X-ray of wrist and pelvis showed severe osteopenia and skeletal immaturity. T: multivitamins and calcium and referral to dietetics and endocrinology. O: Dietetic input successful in widening diet, symptoms and biochemistry resolved in 6 months

Discussion:

The incidence of severe nutrient deficiencies in ASD is unknown, however this paper collates 30 published case reports. In many cases, symptoms had been present for weeks or months and the diagnosis of a deficiency initially missed. Children with ASD should be assessed for coexisting physical and mental health conditions, including feeding problems, at diagnosis (73), and have access to services (including dietitians) which can assess and advise on management. In the absence of validated screening tools for nutritional deficiencies, consensus cut offs such as 'eating less than 20 foods' may be useful to identify those at highest risk (74). All professionals working with children with ASD and feeding problems should be aware of the varying physical and neurological presentations of nutrient deficiencies and the risk of them causing life changing and life threatening illness.

Conclusion

Severe nutrient deficiencies caused by severely selective eating can cause life threatening and sometimes life changing health problems in children with ASD. Early identification and treatment is key. Commissioners should focus on prevention via effective management of the feeding problems that are so common in ASD.

Acknowledgments:

This paper was written as part of work for the author's Masters in Research (Clinical), funded by the Health Education England (HEE) and National Institute for Health Research (NIHR) as part of the Integrated Clinical Academic (ICA) Programme. No conflicts of interest.

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Screening Questions

1. **Was there a clear statement of the aims of the research?**

   Yes / Can't tell / No

   Consider

   - What was the goal of the research?
   - Why it was thought important?
   - Its relevance

2. **Is a qualitative methodology appropriate? Yes / Can't tell / No**

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

➔ **Is it worth continuing? Yes / No**

3. **Is the research design appropriate to address the aims of the research? Yes / Can't tell / No**

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. **Was the recruitment strategy appropriate to the aims of the research? Yes / Can't tell / No**

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. **Was the data collected in a way that addressed the research issue? yes / Can't tell / No**

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered? Yes / Can't tell / No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration? Yes / Can't tell / No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous? Yes / Can't tell / No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account

- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings? Yes / Can't tell / No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers' arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research? Useful, valuable

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Paper 2: Phelps, K. W., Hodgson, J. L., McCammon, S. L. & Lamson, A. L., 2009. Caring for an individual with autism disorder: A qualitative analysis. Journal of Intellectual and Developmental Disability, 34(1), pp. 27-35.

Screening Questions

1. **Was there a clear statement of the aims of the research? Yes / Can't tell / No**

   Consider

   - What was the goal of the research?
   - Why it was thought important?
   - Its relevance

2. **Is a qualitative methodology appropriate? Yes / Can't tell / No**

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

➔ **Is it worth continuing? Yes / No**

3. **Is the research design appropriate to address the aims of the research? Yes / Can't tell / No**

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. **Was the recruitment strategy appropriate to the aims of the research? Yes / Can't tell / No**

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. **Was the data collected in a way that addressed the research issue? Yes / Can't tell / No Semi-structured interview would have given richer results**

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

6. **Has the relationship between researcher and participants been adequately considered? Yes / Can't tell / No**

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration? Yes / Can't tell / No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous? Yes / Can't tell / No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings? Yes / Can't tell / No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers' arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research? Useful due to the sample size.

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Paper 3: Rogers, L. G., Magill-Evans, J. & Rempel, G. R., 2012. Mothers' Challenges in Feeding their Children with Autism Spectrum Disorder—Managing More Than Just Picky Eating. J Dev Phys Disabil, Volume 24, pp. 19-33.

Screening Questions

1. **Was there a clear statement of the aims of the research? Yes / Can't tell / No**

   Consider

   - What was the goal of the research? – Exploring the processes involved in addressing the feeding challenges of young children with ASD from a mother's perspective.
   - Why it was thought important?
   - Its relevance

2. **Is a qualitative methodology appropriate? Yes / Can't tell / No**

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

➔ **Is it worth continuing? Yes / No**

3. **Is the research design appropriate to address the aims of the research? Yes / Can't tell / No Sort of**

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)? Semi-structured interviews and grounded theory process.

4. **Was the recruitment strategy appropriate to the aims of the research? Yes / Can't tell / No**

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue? Yes / Can't tell / No

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered? Yes / Can't tell / No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location

- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration? Yes / Can't tell / No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous? Yes / Can't tell / No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are considered
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings? Yes / Can't tell / No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers' arguments

- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research? Useful

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Paper 4: Werner DeGrace, B., 2004. The everyday occupation of families with children with autism. American Journal of Occupational Therapy, Volume 58, pp. 543-550.

Screening Questions

1. **Was there a clear statement of the aims of the research?**

   Yes / Can't tell / No

   Consider

   - What was the goal of the research?
   - Why it was thought important?
   - Its relevance

2. **Is a qualitative methodology appropriate? Yes / Can't tell / No**

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

➔ **Is it worth continuing? Yes / No**

3. **Is the research design appropriate to address the aims of the research? Yes / Can't tell / No**

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. **Was the recruitment strategy appropriate to the aims of the research? Yes / Can't tell / No**

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study

- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue? Yes / Can't tell / No

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered? Yes / Can't tell / No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration? Yes / Can't tell / No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous? Yes / Can't tell / No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings? Yes / Can't tell / No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers' arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research? Well conducted research with good insight

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Paper 5: Suarez, M. A., Atchison, B. J. & Lagerway, M., 2014. Phenomenological examination of the mealtime experience for mothers of children with autism and food selectivity. American Journal of Occupational Therapy, Volume 68, pp. 102-7.

Screening Questions

1. **Was there a clear statement of the aims of the research? Yes / Can't tell / No**

   Consider

   - What was the goal of the research? To explore the family occupation of mealtime from the perspective of mothers of children with autism and food selectivity
   - Why it was thought important? To inform family-centred care
   - Its relevance

2. **Is a qualitative methodology appropriate? Yes / Can't tell / No**

➔ **Is it worth continuing? Yes / No**

3. **Is the research design appropriate to address the aims of the research? Yes / Can't tell / No**

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)? Only partially

4. **Was the recruitment strategy appropriate to the aims of the research? Yes / Can't tell / No**

HINT: Consider

- If the researcher has explained how the participants were selected – participants from a larger study who agreed to be contacted and met inclusion criteria
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study. Don't justify the age range of 4-12 years old

- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue? Yes / Can't tell / No

HINT: Consider

- If the setting for data collection was justified – yes phone
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) – yes semi-structured interview
- If the researcher has justified the methods chosen - **no**
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? Yes – interview schedule included
- If methods were modified during the study. If so, has the researcher explained how and why? n/a
- If the form of data is clear (e.g. tape recordings, video material, notes etc.) yes
- If the researcher has discussed saturation of data – yes

6. Has the relationship between researcher and participants been adequately considered? Yes / Can't tell / No Not addressed at all

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration? Yes / Can't tell / No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous? Yes / Can't tell / No

HINT: Consider

- If there is an in-depth description of the analysis process YES
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? Phenomenological analysis
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process yes
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account – not mentioned
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation – not covered.

9. Is there a clear statement of findings? Yes / Can't tell / No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers' arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) YES
- If the findings are discussed in relation to the original research question YES

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature? YES -
- If they identify new areas where research is necessary YES
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix 3: Enhancing transparency in reporting the synthesis of qualitative research: the ENTREQ statement

Item	Guide and Description	Included?
1 Aim	State the research question the synthesis addresses.	Yes
2 Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	Yes
3 Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	Yes
4 Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	Yes
5 Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	Yes
6 Electronic search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	Yes
7 Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	Yes
8 Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	Yes
9 Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g., for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development).	Yes
10 Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	Yes
11 Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	Yes
12 Appraisal	Indicate whether the appraisal was conducted	Yes

process	independently by more than one reviewer and if consensus was required.	
13 Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	Yes
14 Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).	Yes
15 Software	State the computer software used, if any.	n/a
16 Number of reviewers	Identify who was involved in coding and analysis.	Yes
17 Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	Yes
18 Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	Yes
19 Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	Yes
20 Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation. 21 Synthesis output Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	Yes

Appendix 4: Participant questionnaire

Participant questionnaire for the project**: A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire.**

Your responses will be kept confidential and only used in the research anonymously. Please answer the following 77 questions as best you can. Please ask for help if you have any problem understanding or reading or writing on this form.

Date:

About you:

1) Your full name_____

2) Your age_____

3) Your gender: male/female/other

4) Your address:_____

_____

5) Which of these best describes your ethnic group? (please tick one)

◯ White British ◯ White Irish ◯ Any other White background

◯ Black or Black British: Caribbean ◯ Black or Black British: African

◯ Any other Black background

◯ Asian or Asian British: Indian ◯ Asian or Asian British: Pakistani

◯ Asian or Asian British: Bangladeshi ◯ Any other Asian background

◯ Mixed: White and Black Caribbean ◯ Mixed: White and Black African

◯ Mixed: White and Asian ◯ Any other mixed background ◯ Chinese

◯ Any other ethnic group ◯ Don't know or prefer not to say

About your child who has Autism Spectrum Disorder (ASD)

(if you have more than one child with ASD please fill in a form for each child):

6) What is your child's name?

7) What is your relationship to the child: mother/father/ other (please state)

_____

8) How old is your child?

9) Are they: male/female

10) Which of these best describes your child's ethnic group? (please tick one)

◯White British ◯ White Irish ◯ Any other White background

◯ Black or Black British: Caribbean ◯ Black or Black British: African

◯ Any other Black background

◯ Asian or Asian British: Indian ◯ Asian or Asian British: Pakistani

◯ Asian or Asian British: Bangladeshi ◯ Any other Asian background

◯ Mixed: White and Black Caribbean ◯ Mixed: White and Black African

◯ Mixed: White and Asian ◯ Any other mixed background ◯ Chinese

◯ Any other ethnic group ◯ Don't know or prefer not to say

11) How old were they when they were diagnosed with ASD? _____

12) Who were they diagnosed by? _____

13) What was their diagnosis: autism / autism spectrum disorder / PDDNOS / Aspergers / other (please state)_____

14) Do they have any other health or development diagnoses or problems? No / Yes (please state)

_____

_____

_____

15) Does s/he join in playing games with other children easily? Yes No

16) Does s/he come up to you spontaneously for a chat? Yes No

17) Was s/he speaking by 2 years old? Yes No

18) Does s/he enjoy sports? Yes No

19) Is it important to him/her to fit in with the peer group? Yes No

20) Does s/he appear to notice unusual details that others miss? Yes No

21) Does s/he tend to take things literally? Yes No

22) When s/he was 3 years old, did s/he spend a lot of time pretending (e.g., play-acting being a superhero, or holding teddy's tea parties)? Yes No

23) Does s/he like to do things over and over again, in the same way all the time? Yes No

24) Does s/he find it easy to interact with other children? Yes No

25) Can s/he keep a two-way conversation going? Yes No

26) Can s/he read appropriately for his/her age? Yes No

27) Does s/he mostly have the same interests as his/her peers? Yes No

28) Does s/he have an interest which takes up so much time that s/he does little else? Yes No

29) Does s/he have friends, rather than just acquaintances? Yes No

30) Does s/he often bring you things s/he is interested in to show you? Yes No

31) Does s/he enjoy joking around? Yes No

32) Does s/he have difficulty understanding the rules for polite behaviour? Yes No

33) Does s/he appear to have an unusual memory for details? Yes No

34) Is his/her voice unusual (e.g., overly adult, flat, or very monotonous)? Yes No

35) Are people important to him/her? Yes No

36) Can s/he dress him/herself? Yes No

37) Is s/he good at turn-taking in conversation? Yes No

38) Does s/he play imaginatively with other children, and engage in role-play? Yes No

39) Does s/he often do or say things that are tactless or socially inappropriate? Yes No

40) Can s/he count to 50 without leaving out any numbers? Yes No

41) Does s/he make normal eye-contact? Yes No

42) Does s/he have any unusual and repetitive movements? Yes No

43) Is his/her social behaviour very one-sided and always on his/her own terms?

Yes No

44) Does s/he sometimes say "you" or "s/he" when s/he means "I"? Yes No

45) Does s/he prefer imaginative activities such as play-acting or story-telling, rather than numbers or lists of facts? Yes No

46) Does s/he sometimes lose the listener because of not explaining what s/he is talking about?

Yes No

47) Can s/he ride a bicycle (even if with stabilisers)? Yes No

48) Does s/he try to impose routines on him/herself, or on others, in such a way that it causes problems? Yes No

49) Does s/he care how s/he is perceived by the rest of the group? Yes No

50) Does s/he often turn conversations to his/her favourite subject rather than following what the other person wants to talk about? Yes No

51) Does s/he have odd or unusual phrases? Yes No

Section C: About your child's eating

Think about mealtimes with your child **during the past 6 months**. Please circle the appropriate number to rate how often the behaviour occurs.

1 = never, almost never 2 = seldom 3 = occasionally 4 = often

5 = almost every meal

52) My child cries or screams during mealtimes.	1	2	3	4	5
53) My child turns his/her face or body away from food.	1	2	3	4	5
54) My child is aggressive during mealtimes (hitting, kicking, scratching)	1	2	3	4	5
55) My child shows self-injurious behavior at meals (scratching, biting self)	1	2	3	4	5
56) My child is disruptive during mealtimes (pushing, throwing things)	1	2	3	4	5
57) My child closes his/her mouth tightly when food is presented.	1	2	3	4	5
58) My child is willing to try new foods.	1	2	3	4	5
59) My child dislikes certain foods and will not eat them.	1	2	3	4	5
60) My child prefers the same foods at each meal.	1	2	3	4	5
61) My child accepts or prefers a variety of foods.	1	2	3	4	5

Think about mealtimes with your child **during the past 6 months**. Please circle the appropriate number to rate how often the behavior occurs.

0 = not at all 1 = one to 10 times 2 = more than 10 times

62) Cannot independently feed	0	1	2
63) Problem behaviors increase during meals	0	1	2
64) Does not demonstrate ability to chew	0	1	2
65) Will only eat select types of foods	0	1	2
66) Steals or attempts to steal food	0	1	2
67) Only eats a small amount of food presented	0	1	2
68) Will continue to eat as long as food presented	0	1	2
69) Steals or attempts to steal food outside mealtimes	0	1	2
70) Eats large amounts in short time	0	1	2
71) Swallows without chewing sufficiently	0	1	2
72) Regurgitates or re-swallows food	0	1	2
73) Pushes food away or attempts to leave area	0	1	2
74) Only eats foods at certain temperatures	0	1	2
75) Vomits during or right after meals	0	1	2
76) Only eats certain textures	0	1	2

75) Please record everything your child at and drank in the last 24 hours or on a typical day, whichever best reflects their dietary intake. Be as specific as possible. Include all drinks, condiments, portion sizes and any dietary supplements**.**

Time	**Details of Food and Drink**	**Amount consumed**

Thankyou for your participation.

Please return your completed form to me at connorz@uni.coventry.ac.uk

or Zoe Connor, xxxxxxx

Appendix 5: Focus group schedule

Prep for the group: night before:

- Ensure you have all the forms needed
    - 1 x copy of moderator's guide (this one)
    - 1 x copy per participant of the participant info sheet
    - 2 x copy per participant of the consent form
    - 2 x copies per participant of the video/audio/picture consent form
- Biscuits
- Fully charged Dictaphone
- Dictaphone charger
- Fully charged iPad with enough space in memory for the recording
- IPad charger
- A notepad
- Pens for enough participants
- Name tents for each participant
- Name list
- Room booking

Prep for the group: hour before:

- Ensure you have
    - cups for tea and coffee and water
    - milk
    - sugar
    - tea and coffee
    - hot water / kettle
    - biscuits

Strategies:

- The focus group moderator has a responsibility to adequately cover all prepared questions within the time allotted. S/he also has a responsibility to get all participants to talk and fully explain their answers. Some helpful probes include:
    - "Can you talk about that more?"
    - "Help me understand what you mean"
    - "Can you give an example?"
- It is good moderator practice to paraphrase and summarize long, complex or ambiguous comments. It demonstrates active listening and clarifies the comment for everyone in the group.

- Because the moderator holds a position of authority and perceived influence, s/he must remain neutral, refraining from nodding/raising eyebrows, agreeing/disagreeing, or praising/denigrating any comment made.
- Here are some strategies for dealing with different group dynamic issues:
    - Self-appointed experts: "Thank you. What do other people think?"
    - The dominator: "Let's have some other comments."
    - The rambler: Stop eye contact; look at your watch; jump in at their inhale.
    - The shy participant: Make eye contact; call on them; smile at them.
    - The participant who talks very quietly: Ask them to repeat their response more loudly.

1. Introduction

a. **Welcome**

"*Welcome and thank you for coming to this focus group. Each of your points of view are important to us. We know that you are very busy and we greatly appreciate your contribution to this project. This interview is not a test, nor should it be in any way viewed as a series of questions with right or wrong answers. Remember, we are very interested in what you think and feel. We want to know your opinions on these issues, and we are certainly not interested in your agreeing with the opinions and feelings of others. There may be times, however, when you do, and it is appropriate for you to let us know that as well. "*

b. **Statement of purpose of interview**

"*The purpose of this focus group interview is to determine your ideas and opinions about the topic of caring for a child with autism spectrum disorder who has eating problems and the professional support you have received and desire.*"

c. **Guidelines to follow during the interview**

"*There are a few guidelines I would like to ask you to follow during the focus group interview. First, you do not need to speak in any particular order. When you have something to say, please do. Second, please do not speak while someone else is talking. Sometimes, the exchanges get emotional, and it is tempting to 'jump in' which someone is talking, but we ask you to refrain from doing so. Third, remember that there are many people in the group and that it is important that we obtain the point of view of each one of you. Fourth, you do not need to agree with what everyone or anyone in the group says, but you do need to state your point of view without making any negative comments or 'put downs'. Finally, because we have limited time together, I may need to stop you and to redirect our discussion. What questions do you have? ... Okay, let's begin.* "

2. **Establish Easy and Nonthreatening Questions**

    a. **The initial questions should be general and less threatening**

    "1. Who is in your household?"

3. **Participatory photography discussion**

    a. **"2. Thank you for sharing your photographs. Please spend a few minutes looking at the photographs we have displayed around the room."**

"Tell me about your child's eating problems:

What eating problems does your child have?

How does it affect your child and you and your family?

Which of your or others' photos represent these issues for you. Tell me about your photos"

4. **Establish More Difficult Questions**
    a. **The more difficult or personal questions should be determined**

"3. What professional help with your child's eating problems have you received? What has been the best help you've received?

4. In an ideal world - what professional help would you have liked/would you like? What would it be, from whom and where would it be provided?

5. Is there anything else you would like to tell me about your child's eating problems?"

3. Wrap-up

a. **Identify and organise the major themes from the participant's responses**

b. **Ensure that any conversational points not completed are mentioned**

4. Member check

a. **Determine how each member perceives selected issues**

5. Closing Statements

a. **Request anonymity of information**

"*As we come to a close, I need to remind each of you that the audiotape will be transcribed, you will be assigned false names for the purpose of the transcript and data analysis so that you will remain anonymous, and then the tape will be destroyed. We ask that you refrain from discussing the comments of group members and that you respect the right of each member to remain anonymous. "*

b. **Answer any remaining questions**

"*Are there any questions I can answer? "*

c. **Express thanks**

"*Thank you for your contribution to this project. This was a very successful interview and your honest and forthright responses will be an enormous asset to our work. Again, we very much appreciate your involvement*"

When the focus group is complete the moderator thanks all participants.

- Immediately after all participants leave, the moderator and assistant moderator debrief while the recorder is still running and label all tapes and notes with the date, time (if more than one group per day), and name of the group.

Appendix 6: Focus groups participant information sheet

Title of Project: A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire.

Name of researcher: Zoe Connor, email. connorz@uni.coventry.ac.uk

Dear focus group participant,

Thank you for your participation in this research which is conducted by Zoe Connor of Lewisham and Greenwich NHS Trust and Coventry University. This research aims to explore your experiences of caring for a child with autism spectrum disorder (ASD) who has eating problems and the professional support you have received and desire.

Your participation is important for the completion of this research. If you have any questions about this research, please do not hesitate to ask.

Background to the research

Many children with ASD have eating problems. The impact this has on their family's life is not well-documented. Support for eating problems may come from a wide variety of professionals – the effectiveness and parent satisfaction with current support in Lewisham is not known. Your experiences and views will be sought in order to better design services in Lewisham.

What's involved?

You will be asked to attend a 'focus group' – a group discussion with one or two facilitators and up to 7 other parents of children with ASD. Prior to the session, you will be asked to submit 5 photos which you feel represent something related to your experiences of your child having eating problems. You will be given guidance on taking or selecting these photos. The focus group will be held during school hours. Before the focus group you will be asked to fill in a few forms about you and your child. In the focus group, you will be invited to discuss your chosen

photos and asked a number of questions related to your experience of eating problems your child has and the support you have received and desire. The discussion will last approximately 1-2 hours. The focus group will be recorded on a Dictaphone-type device. Please be assured that data collected from the focus group discussion will be confidential and used for academic purposes only. Data will also be coded appropriately and reporting of results will be anonymous. Likely outputs include academic publications and dissemination of findings to paediatric professionals in Lewisham and Greenwich NHS Trust, and autism charities.

What are the possible benefits of taking part?

In taking part you will be helping in the evaluation and design of services to support parents of children with ASD who have eating problems in Lewisham. Many people enjoy the process of participatory photography and focus groups.

What are the possible disadvantages of taking part?

It is possible that you may feel a bit upset or uncomfortable in discussing your child's eating problems. The focus group facilitator will set ground rules for all of the group to maintain each-others' confidence and to be supportive and non-critical.

Once again, thank you for participating in this research. If you have any questions about this research after the focus group discussion, please contact Zoe Connor at connorz@uni.coventry.ac.uk or her Head of Department Dr Deborah Lycett at deborah.lycett@coventry.ac.uk

Version 1. Date: 12th September 2016

Appendix 7: Participant consent form

Title of Project: A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire.

Name of researcher: Zoe Connor, email. connorz@uni.coventry.ac.uk

Participant Identification number:	Please initial box
1. I confirm that I have read the information sheet dated 12th September 2016 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.	
1. I agree to my interview being audio recorded.	
2. I agree to the use of anonymised quotes in publications and presentations.	
3. I agree to the use of my anonymised photographs being used in publications and presentations.	
4. I agree to take part in the above study.	

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Please send this form to me Zoe Connor at xxxxxxx or connorz@uni.coventry.ac.uk

Appendix 8: Interview schedule

Prep before interview:

- Ensure the following have been completed:
    - Photos received
    - Consent forms (on BOS)
    - Questionnaire (on BOS)
- Charge Dictaphone
- Phone charged
- Pen and paper
- Participant phone number

5. Introduction

a. **Welcome**

"T*hank you for agreeing to this interview, I appreciate you giving up your time for this project. I just wanted to recap on some key things about this research and our interview today.*

b. **Statement of purpose of interview**

"*The purpose of this interview is to determine your ideas and opinions about the topic of caring for a child with autism spectrum disorder who has eating problems and the professional support you have received and desire.*"

c. **Reminder about recording**

"I am recording our interview. After the interview, I will be typing it up, changing your name to make it anonymous. I will then be looking at your responses alongside other parents' responses to analyse the key topics. I will email you with my results and any papers I publish from my research. Do you have any more questions about how your interview and photos will be used?"

6. **Establish Easy and Nonthreatening Questions**

    a. **The initial questions should be general and less threatening**

    "1. Let's start. Who is in your household?"

    "Tell me a bit about your child with ASD"

7. **Participatory photography discussion**

    a. **"2. Thank you for sharing your photographs. Please spend a few minutes looking at the photographs we have displayed around the room."**

    "Tell me about your child's eating problems:

    What eating problems does your child have?

    How does it affect your child and you and your family?

    Which of your photos represent these issues for you? Tell me about your photos"

8. **Establish More Difficult Questions**

    a. **The more difficult or personal questions should be determined**

    "3. What professional help with your child's eating problems have you received?

What has been the best help you've received?

"4. In an ideal world - what professional help would you have liked/would you like? What would it be, from whom and where would it be provided?

"Have you ever tried any special diets or supplement for your child? Tell me more about that"

5. Is there anything else you would like to tell me about your child's eating problems?"

6. Wrap-up

a. **Identify and organise the major themes from the participant's responses**

b. **Answer any remaining questions**

"*Are there any questions I can answer?"*

c. **Express thanks**

"*Thank you for your honest and forthright responses which will be an enormous asset to our work. Again, we very much appreciate your involvement*"

Appendix 9: Interview participant information sheet

Title of Project: A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire.

Name of researcher: Zoe Connor, email. connorz@uni.coventry.ac.uk

Dear interview participant,

Thank you for your participation in this research which is conducted by Zoe Connor of Lewisham and Greenwich NHS Trust and Coventry University. This research aims to explore your experiences of caring for a child with autism spectrum disorder who has eating problems and the professional support you have received and desire.

Your participation is important for the completion of this research. If you have any questions about this research please do not hesitate to ask.

Background to the research

Many children with ASD have eating problems. The impact this has on their family's life is not well-documented. Support for eating problems may come from a wide variety of professionals – the effectiveness and parent satisfaction with current support in Lewisham is not known. Your experiences and views will be sought in order to better design services in Lewisham.

What's involved?

You will be interviewed over the phone for up to an hour – by the researcher. Prior to the interview, you will be asked to fill in 2 forms – either on line or on paper. You will also be asked to submit 5 photos which you feel represent something related to your experiences of your child having eating problems. You will be given guidance on taking or selecting these photos. The phone interview will be arranged at a time most convenient to you – which can be on weekdays, the evening or at the weekend. In the interview, you will be invited to discuss your chosen photos and asked a number of questions related to your experience of eating problems your child has and the support you have received and desire. The interview will be recorded. Please be assured that

data collected from the interview will be confidential and used for academic purposes only. Data will also be coded appropriately and reporting of results will be anonymous. Likely outputs include academic publications and dissemination of findings to paediatric professionals in Lewisham and Greenwich NHS Trust, and autism charities.

What are the possible benefits of taking part?

In taking part you will be helping in the evaluation and design of services to support parents of children with ASD who have eating problems in Lewisham. Many people enjoy the process of being interviewed.

What are the possible disadvantages of taking part?

It is possible that you may feel a bit upset or uncomfortable in discussing your child's eating problems. The interviewer will be supportive and non-critical.

Once again, thank you for participating in this research. If you have any questions about this research after your interview, please contact Zoe Connor at connorz@uni.coventry.ac.uk or her Head of Department Dr Deborah Lycett at deborah.lycett@coventry.ac.uk

Version 2. Date: 11th November 2016

Appendix 10: Participatory photography guide

A Guide to Taking and Submitting Photos

Thank you for agreeing to taking part in my project**: A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire**.

As part of this project I want you to take some photos and send them me for discussion in our interview.

I want you to send me 5 photos that help to show me: "How do your child's eating problems affect them, you and your family?"

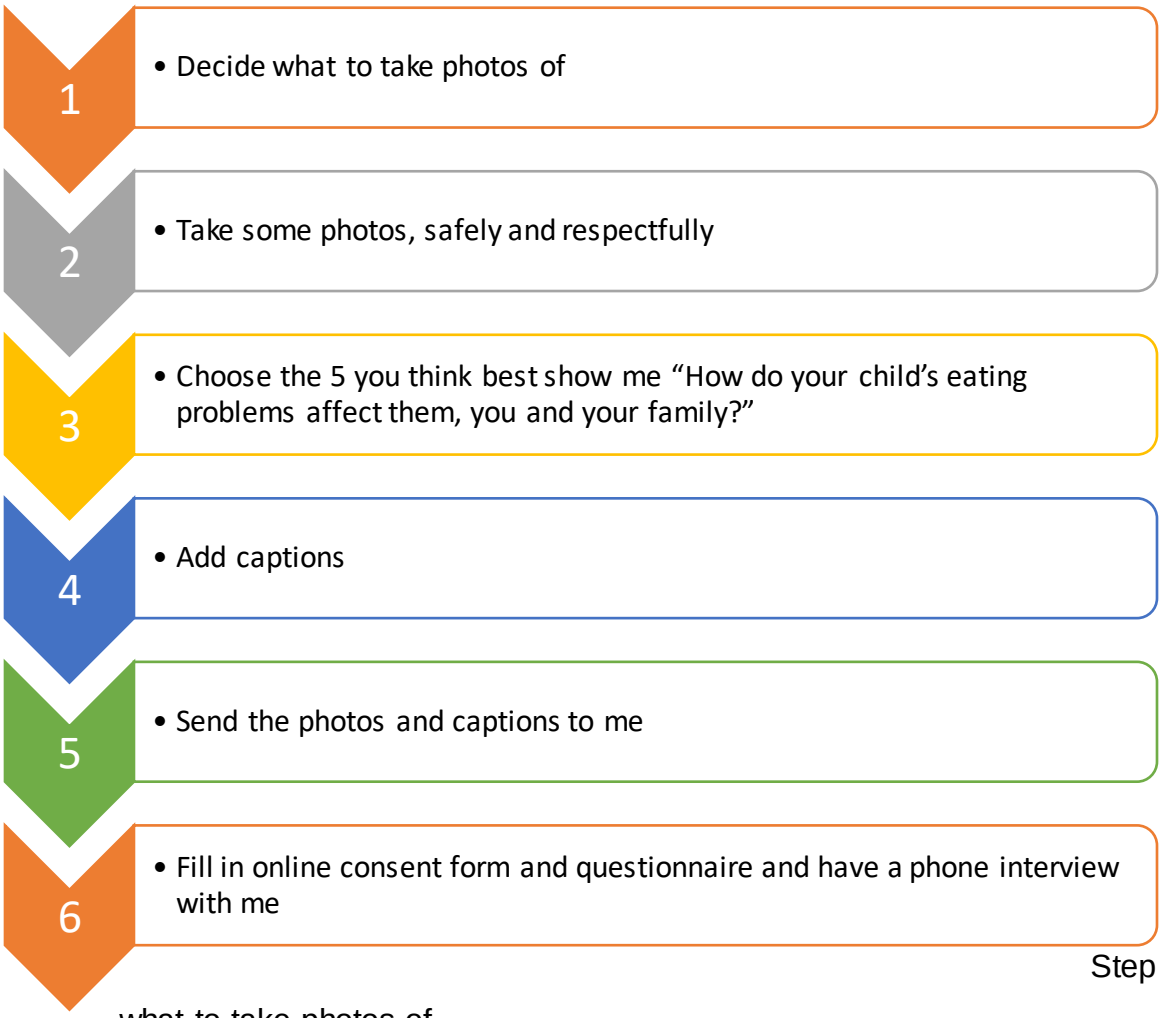
This guide explains the steps I want you to take – summarised in figure 1. Please read the guide carefully.

If you have any questions having read this guide please don't hesitate to contact me on connorz@uni.coventry.ac.uk or my personal number: xxxxxxxxx.

Many thanks,

Zoe Connor

Paediatric Research Dietitian



Step 1) Decide what to take photos of

I want you to send me 5 photos that help to show me: "How do your child's eating problems affect them, you and your family?"

This is your chance to show me through your eyes what your child's eating problems is and how it affects you. You can see the sort of photos that people have included in other participatory photo projects (sometimes called PhotoVoice) in these online videos:

- Photovoice - Parents of Children with Special Needs - www.youtube.com/watch?v=j44wCSWnWfE
- Photovoice – Homelessness - www.youtube.com/watch?v=EgBLFtH7910

Make a list in the box below of all the different things that you could take photos of – I've put a few of my own ideas just to help (you don't need to use any of these ideas – you can be more creative or abstract if you like!). If you are stuck for ideas ask other family and friends to help you come up with ideas:

- Plate of favourite food
- Food cupboard with all favourite foods in
- Supermarket receipt showing range of favourite foods
- Before and after picture of a meal
- Picture of the mess after a meal (or lack of)
- Picture of your child eating showing where they usually eat e.g. from the back of them
- Picture showing how your child's eating makes you feel e.g. of part of your face, or something symbolic
- Picture showing how your child's eating makes you feel e.g. of part of your face, or something symbolic
- Picture of a reward chart of another motivator you use
- Picture of an appointment letter (with identifying info blanked out)

Your ideas for things to take photos of that help to show me: "How do your child's eating problems affect them, you and your family?"

Step 2) Take some photos, safely and respectfully

What should I take the photos with?

Any type of camera is fine. Most important is a camera that is easy for you to use. I will be asking you to send me your photos digitally, so it is easiest to use a digital camera – the one on your phone is fine. If you don't have a camera – can you borrow one? Can a friend or family member help you take the photos with their phone or digital camera? If you don't have a camera to use please let me know and we can discuss other options.

What should I consider before taking photos?

1) Stay safe!
   Make sure you are "safe" when you take the picture. For example:
   Stand on a solid surface.
   Look before you step into or cross a street.
   Be aware of things around you, like traffic.

2) Ask permission
   Always ask permission before taking people's photos for this project.

If you want to use photos of people that can be recognised from the photo you will need to ask them to sign a photo consent form – see page x.

NB. You don't need permission if:

- someone is in the background in a public place like a park
- someone is far away in a photo and can't be recognised
- someone can't be recognised in a picture e.g. if it is of the back of their head or just of their hand or mouth
- someone walks into the view in a picture you are taking

3) Be respectful.

If certain people don't want their photo taken, respect their feelings.

4) Be prepared.

Be ready to explain about the project to family, friends, or strangers, if they ask what you are doing. A simple explanation is: "I am part of a research project looking at how eating problems affect children and their families. We are taking photographs of our lives and talking about them with other people in our group. Thank you for letting me take your picture."

5) Respect the lives and safety of others.

When you take photos, think of people’s safety first, and be respectful of their lives.

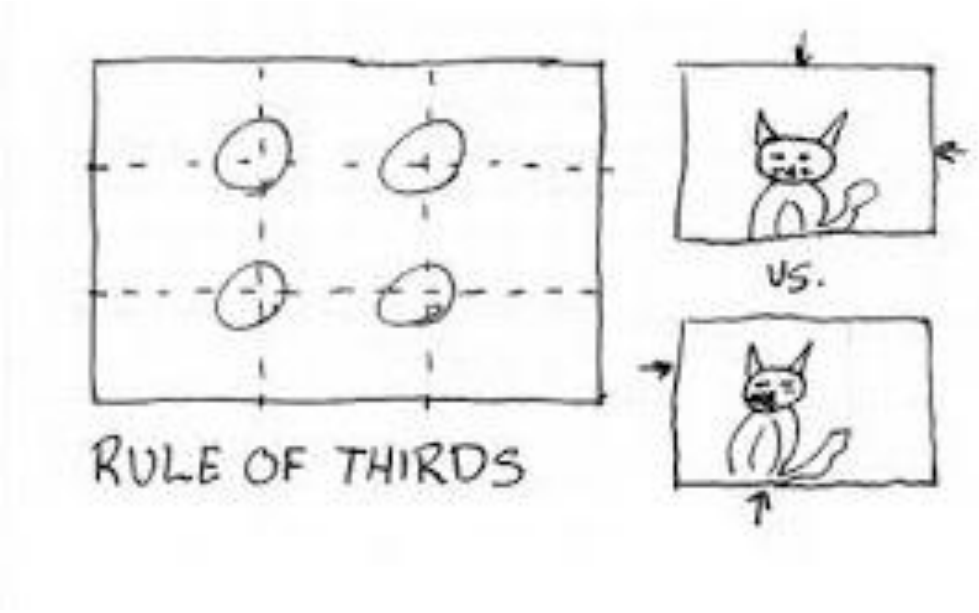
What if I'm rubbish at taking photos?

Photo quality is not important. You sharing your experiences through photographs is what matters. Below are some tips for taking better photographs:

- To prevent blurry pictures, hold your elbows close to your sides, and hold your breath when you press the button.
- Keep your finger away from the lens!
- Try using a flash – even if the photo is in good light – and keep your finger away from the flash
- Try different angles
- Try different points of view
- Keep the sun to your back, or to the side
- Try getting closer up and letting your 'subject' (your main thing of interest in the photo) fill the screen
- Instead of putting the key parts of your 'subject' in the middle of the photo try putting them roughly where the circles are below in Figure 2 (this is a common photography rule called the 'rule of thirds')

.

Figure 2: Rule of thirds - source https://www.flickr.com/photos/mpclemens/4287972839 Creative Commons: Mentally divide your frame into thirds, and try to put the focus of the image along a line or at an intersection of thirds, not dead centre



Keep notes

You may want to keep notes whilst taking your photos – why did you choose the photo? What were you trying to show? How did the situation make you feel? This will help you with adding captions in step 4.

Store your photos carefully

Make sure you store your photos carefully and don't delete them e.g. transfer them to a computer or put them in a file on your camera or phone

Step 3) Choose 5

If you have taken more than 5 photos then you need to narrow it down to 5 that best help to show me: "How do your child's eating problems affect them, you and your family?"

You might want to narrow it down to 10 then discuss with a family member or friend out loud what they mean to you, this might help you choose the 5 that best 'tell your story'

Step 4) Add captions

This is an important step.

Write a caption for each photo. Write it 'from your heart' – as if you were talking to someone else about your photos. If writing is hard, dictate your captions to someone else to write down for you.

If you can't think what to write then think about the answer to these questions:

P: Describe your photo?

H: What is happening in your picture?

O: Why did you take a picture of this?

T: What does this picture tell us about your life?

O: How can this picture provide opportunities for us to improve life?

Think about adding feelings in too – how does this situation make you feel – what is its impact on you.

For example, here is one of my pictures – taken a couple of weeks ago whilst having lunch with my 2-year-old nephew:

One caption could be:

> **This is a typical mealtime with George. We're lucky if more than one spoonful goes into his mouth. It makes me so stressed how messy it is. I get through so many changes in clothes.**

Another caption could be:

> **This was a breakthrough with George last week. He has never touched yogurt before. Not much went into his mouth, but he's playing with it – which is a start. I felt so happy!**

Or another could be:

> **This is a picture of George playing with yogurt when he was 2 years on. Little did I know that 5 years later he still wouldn't have progressed from being fed with a spoon and making a mess. Feeding him takes so much patience, takes up so much of my day and there doesn't seem to be a light at the end of the tunnel. It's so frustrating, and I get angry about it too!**

Can you see how important the captions are – they will help me when I am using the photos to tell other people your stories! (NB – you can use real or fake names in your captions – I will make sure any real names are changed to fake names or blanked out before I use any in my research.)

The captions don't need to be too long – 2-5 sentences are ideal.

Sometimes once you have done this stage you might have got ideas for different photos you'd like to choose instead – its fine to go away and take more photos and add captions and change your mind – as long as you choose 5 photos and send them to me in time!!

Step 5) Send the photos and captions to me

Please send the photos and captions to me before your interview- so I can look at them while we discuss them.

You can email them directly to me at connorz@uni.coventry.ac.uk. If you wish to send your photos via an encrypted method then please use the free encrypted email service Virtru (www.virtru.com) or upload your emails to a free Dropbox account and send me a link to them (www.dropbox.com). If you wish to include old photos that aren't digital you can take a photo of them with your digital camera to send them to me.

For example, your email to me might say:

Hi Zoe,

Please find attached my 5 photos.

Caption 1 for the photo at the table (IMG006753):

Caption 2 for the photo of the fridge contents (IMG009832):

etc.

Also attached is the consent form from my partner for having her photo included in photo 3.

Step 6) Fill in the online questionnaire and consent form and have a phone interview with me

Other questions

What if I want to use a photo that has someone's face in?

If you want to use a photo that has someone in that is identifiable then there are a few options:

1) You crop (cut part of the photo) the photo so the person isn't identifiable in it
2) You blur out the person's face (e.g. using a free tool like http://www.photohide.com or www.facepixelizer.com)
3) You obscure part of the picture so it is not identifiable

For example, here is an old photo of me with the different options applied:




If you want to send me a photo and for me to edit it so you can't see the faces of the people on it – I can help with that.

If the person is happy and willing to have their photo included without being made anonymous then please get them to sign the form on the following page and include a copy of it with your photos.

Any other questions please don't hesitate to contact me!

Thanks - Zoe

Photo Consent Form

I [Insert your name here]…… am part of a research project investigating what it is like to have a child with eating problems. We are taking photographs of our lives and talking about them with other people in our group. The researcher Zoe Connor (connorz@uni.coventry.ac.uk) is doing this project via Coventry University and Lewisham Hospital and will use these photos for disseminating her research e.g. in exhibitions, conferences and journals.

Please sign this form if you agree to let me take your photograph for this project.

	Please initial box
5. I agree to having my photo taken for this project, used in discussions and in publications and presentations.	☐
6. I wish my face to be obscured using pixilation or other methods.	☐
7. I am happy for my face to be used without pixilation or other methods.	☐

_____ _____ _____

Name of person having photo taken Date Signature

---------- ---------- ----------

Name of parent if giving consent Date Signature

for someone under 18 having photo taken

_____ _____ _____

Name of Person taking consent Date Signature

Appendix 11: Photo release form

Print Consent Form

I, the undersigned, consent to the use of my words and images being used within Coventry University publications or video case studies. I understand that this may be used for educational, marketing, and/or commercial purposes, and that copyright will reside with Coventry University.

I acknowledge that the quote or image may also be used in, and distributed by, media pertaining to Coventry University's activities other than a printed publication, such as, but not limited to CD-ROM, DVD or the World Wide Web.

Copyright restrictions placed on Coventry University publications and case studies prevent content being sold or used by way of trade without the expressed permission of the University, as copyright holder. Images and recordings may not be edited, amended or re-used without permission from Zoe Connor on behalf of Coventry University. Personal details of those taking part are not made available to third parties.

Please complete the Participant details below and return the form to Zoe Connor the University contact;

Participant's details:

Name:

Signature:

Date:

Please return this form to me Zoe Connor xxxxxxx or connorz@uni.coventry.ac.uk

Appendix 12: Coventry University ethics approval

Medium to High Risk Research Ethics Approval

Project Title

A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire

Record of Approval

Principal Investigator

I **request an ethics peer review** and confirm that I have answered all relevant questions in this checklist honestly.	X
I confirm that I will carry out the project in the ways described in this checklist. I will immediately suspend research and request new ethical approval if the project subsequently changes the information I have given in this checklist.	X
I confirm that I, and all members of my research team (if any), have read and agreed to abide by the Code of Research Ethics issued by the relevant national learned society.	X
I confirm that I, and all members of my research team (if any), have read and agreed to abide by the University's Research Ethics, Governance and Integrity Framework.	X

Name: Zoe Connor .....

Date: 10/11/2015 .....

Student's Supervisor (if applicable)

I have read this checklist and confirm that it covers all the ethical issues raised by this project fully and frankly. I also confirm that these issues have been discussed with the student and will continue to be reviewed in the course of supervision.

Name: Deborah Lycett.....

Date: 10/03/2016 .....

Reviewer (if applicable)

Date of approval by anonymous reviewer: 18/03/2016

Medium to High Risk Research Ethics Approval Checklist

Project Information

Project Ref	P38615
Full name	Zoe Connor
Faculty	Faculty of Health and Life Sciences
Department	FRC Technology Enabled Health Research (CTEHR)
Supervisor	Deborah Lycett
Module Code	M004MRDC
EFAAF Number	
Project title	A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire
Date(s)	01/01/2016 - 31/12/2017
Created	10/11/2015 14:05

Project Summary

A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire

Names of Co-Investigators and their organisational affiliation (place of study/employer)	
Is the project self-funded?	YES
Who is funding the project?	National Institute of Health Research
Has the funding been confirmed?	YES
Are you required to use a Professional Code of Ethical Practice appropriate to your discipline?	YES
Have you read the Code?	YES

Project Details

What is the purpose of the project?	This research aims to: examine the experiences of parents/guardians of children with ASD in Lewisham who have eating problems; the support they have received; and the additional support they would like.
What are the planned or desired outcomes?	The research questions are: 1) How does caring for a child with ASD who has eating problems affect that child, their parents/guardians and their wider family? 2) How is the professional support that parents/guardians of children with ASD and eating problems receive in Lewisham perceived? 3) What further professional support would that parents/guardians of children with ASD and eating problems in Lewisham like?

Explain your research design	The research will study the phenomena of individuals using a pragmatic qualitative research approach, leaning towards the beginning of a participatory action research cycle in developing better services in conjunction with the service users.
Outline the principal methods you will use	Focus groups, participatory photography and semi-structured interviews of parents of children with autism spectrum disorder and eating problems in Lewisham.
Are you proposing to use an external research instrument, validated scale or follow a published research method?	NO
If yes, please give details of what you are using	
Will your research involve consulting individuals who support, or literature, websites or similar material which advocates, any of the following: terrorism, armed struggles, or political, religious or other forms of activism considered illegal under UK law?	NO

Are you dealing with Secondary Data? (e.g. sourcing info from websites, historical documents)	NO
Are you dealing with Primary Data involving people? (e.g. interviews, questionnaires, observations)	YES
Are you dealing with personal or sensitive data?	NO
Is the project solely desk based? (e.g. involving no laboratory, workshop or offcampus work or other activities which pose significant risks to researchers or participants)	NO
Are there any other ethical issues or risks of harm raised by the study that have not been covered by previous questions?	NO
If yes, please give further details	

DBS (Disclosure & Barring Service) formerly CRB (Criminal Records Bureau)

Question		**Yes**	**No**
1	Does the study require DBS (Disclosure & Barring Service) checks?		X
	If YES, please give details of the serial number, date obtained and expiry date		
2	If NO, does the study involve direct contact by any member of the research team		
	a) with children or young people under 18 years of age?		X
	b) with adults who have learning difficulties, brain injury, dementia, degenerative neurological disorders?		X
	c) with adults who are frail or physically disabled?		X

	d) with adults who are living in residential care, social care, nursing homes, re-ablement centres, hospitals or hospices?		X
	e) with adults who are in prison, remanded on bail or in custody?		X
	If you have answered YES to any of the questions above please explain the nature of that contact and what you will be doing		

External Ethical Review

Question		**Yes**	**No**
1	Will this study be submitted for ethical review to an external organisation? (e.g. Another University, Social Care, National Health Service, Ministry of Defence, Police Service and Probation Office)	X	
	If YES, name of external organisation	Lewisham and Greenwich NHS Trust	
2	Will this study be reviewed using the IRAS system?		
3	Has this study previously been reviewed by an external organisation?		

Confidentiality, security and retention of research data

Question		**Yes**	**No**
1	Are there any reasons why you cannot guarantee the full security and confidentiality of any personal or confidential data collected for the study?		X
	If YES, please give an explanation		

2	Is there a significant possibility that any of your participants, and associated persons, could be directly or indirectly identified in the outputs or findings from this study?		X
	If YES, please explain further why this is the case		
3	Is there a significant possibility that a specific organisation or agency or participants could have confidential information identified, as a result of the way you write up the results of the study?		X
	If YES, please explain further why this is the case		
4	Will any members of the research team retain any personal of confidential data at the end of the project, other than in fully anonymised form?		X
	If YES, please explain further why this is the case		
5	Will you or any member of the team intend to make use of any confidential information, knowledge, trade secrets obtained for any other purpose than the research project?		X
	If YES, please explain further why this is the case		
6	Will you be responsible for destroying the data after study completion?	X	
	If NO, please explain how data will be destroyed, when it will be destroyed and by whom		

Question			Yes	No
1	Will all the participants be fully informed BEFORE the project begins why the study is being conducted and what their participation will involve?		X	
	If NO, please explain why			
2	Will every participant be asked to give written consent to participating in the study, before it begins?		X	
	If NO, please explain how you will get consent from your participants. If not written consent, explain how you will record consent			
3	Will all participants be fully informed about what data will be collected, and what will be done with this data during and after the study?		X	
	If NO, please specify			
4	Will there be audio, video or photographic recording of participants?		X	
	Will explicit consent be sought for recording of participants?		X	
	If NO to explicit consent, please explain how you will gain consent for recording participants			
5	Will every participant understand that they have the right not to take part at any time, and/or withdraw themselves and their data from the study if they wish?		X	
	If NO, please explain why			

6	Will every participant understand that there will be no reasons required or repercussions if they withdraw or remove their data from the study?	X	
	If NO, please explain why		
7	Does the study involve deceiving, or covert observation of, participants?		X
	Will you debrief them at the earliest possible opportunity?		
	If NO to debrief them, please explain why this is necessary		

Risk of harm, potential harm and disclosure of harm

Question		**Yes**	**No**
1	Is there any significant risk that the study may lead to physical harm to participants or researchers?		X
	If YES, please explain how you will take steps to reduce or address those risks		
2	Is there any significant risk that the study may lead to psychological or emotional distress to participants?		X
	If YES, please explain how you will take steps to reduce or address those risks		
3	Is there any risk that the study may lead to psychological or emotional distress to researchers?		X
	If YES, please explain how you will take steps to reduce or address those risks		

4	Is there any risk that your study may lead or result in harm to the reputation of participants, researchers, or their employees, or any associated persons or organisations?		X
	If YES, please explain how you will take steps to reduce or address those risks		
5	Is there a risk that the study will lead to participants to disclose evidence of previous criminal offences, or their intention to commit criminal offences?		X
	If YES, please explain how you will take steps to reduce or address those risks		
6	Is there a risk that the study will lead participants to disclose evidence that children or vulnerable adults are being harmed, or at risk or harm?	X	
	If YES, please explain how you will take steps to reduce or address those risks	Any safeguarding concerns that are highlighted during the study will be dealt with by following the standard procedures in Lewisham and Greenwich NHS Trust.	
7	Is there a risk that the study will lead participants to disclose evidence of serious risk of other types of harm?		X
	If YES, please explain how you will take steps to reduce or address those risks		
8	Are you aware of the CU Disclosure protocol?	X	

Payments to participants

Question	**Yes**	**No**

1	Do you intend to offer participants cash payments or any kind of inducements, or reward for taking part in your study?		X
	If YES, please explain what kind of payment you will be offering (e.g. prize draw or store vouchers)		
2	Is there any possibility that such payments or inducements will cause participants to consent to risks that they might not otherwise find acceptable?		
3	Is there any possibility that the prospect of payment or inducements will influence the data provided by participants in any way?		
4	Will you inform participants that accepting payments or inducements does not affect their right to withdraw from the study at any time?		

Capacity to give valid consent

Question		Yes	No
1	Do you propose to recruit any participants who are:		
	a) children or young people under 18 years of age?		X
	b) adults who have learning difficulties, mental health condition, brain injury, advanced dementia, degenerative neurological disorders?		X
	c) adults who are physically disabled?		X
	d) adults who are living in residential care, social care, nursing homes, re-ablement centres, hospitals or hospices?		X
	e) adults who are in prison, remanded on bail or in custody?		X
	If you answer YES to any of the questions please explain how you will overcome any challenges to gaining valid consent		
2	Do you propose to recruit any participants with possible communication difficulties, including difficulties arising from limited use of knowledge of the English language?		X
	If YES, please explain how you will overcome any challenges to gaining valid consent		
3	Do you propose to recruit any participants who may not be able to understand fully the nature of the study, research and the implications for them of participating in it or cannot provide consent themselves?		X

	If YES, please explain how you will overcome any challenges to gaining valid consent	

Recruiting Participants

Question		Yes	No
1	Do you propose to recruit any participants who are:		
	a) students or employees of Coventry University or partnering organisation(s)?		X
	If YES, please explain if there is any conflict of interest and how this will be addressed		
	b) employees/staff recruited through other businesses, voluntary or public sector organisations?		X
	If YES, please explain how permission will be gained		
	c) pupils or students recruited through educational institutions (e.g. primary schools, secondary schools, colleges)?		X
	If YES, please explain how permission will be gained		
	d) clients/volunteers/service users recruited through voluntary public services?		X
	If YES, please explain how permission will be gained		

e) participants living in residential care, social care, nursing homes, re-ablement centres hospitals or hospices?			X
If YES, please explain how permission will be gained			
f) recruited by virtue of their employment in the police or armed forces?			X
If YES, please explain how permission will be gained			
g) adults who are in prison, remanded on bail or in custody?			X
If YES, please explain how permission will be gained			
h) who may not be able to refuse to participate in the research?			X
If YES, please explain how permission will be gained			

Online and Internet Research

Question		**Yes**	**No**
1	Will any part of your study involve collecting data by means of electronic media (e.g. the Internet, e-mail, Facebook, Twitter, online forums, etc)?		X
	If YES, please explain how you will obtain permission to collect data by this means		
2	Is there a possibility that the study will encourage children under 18 to access inappropriate websites, or correspond with people who pose risk of harm?		X

	If YES, please explain further				
3	Will the study incur any other risks that arise specifically from the use of electronic media?				X
	If YES, please explain further				
4	Will you be using survey collection software (e.g. BoS, Filemaker)?				X
	If YES, please explain which software				
5	Have you taken necessary precautions for secure data management, in accordance with data protection and CU Policy?			X	
	If NO	please explain why not			
	If YES	Specify location where data will be stored	Encrypted USB flash drive		
		Planned disposal date	31/12/2017		
		If the research is funded by an external organisation, are there any requirements for storage and disposal?			X
		If YES, please specify details			

Laboratory/Workshops

Question		**Yes**	**No**
1	Does any part of the project involve work in a laboratory or workshop which could pose risks to you, researchers or others?		X

	If YES: If you have risk assessments for laboratory or workshop activities you can refer to them here & upload them at the end, or explain in the text box how you will manage those risks	

Research with non-human vertebrates

Question		Yes	No
1	Will any part of the project involve animal habitats or tissues or nonhuman vertebrates?		X
	If YES, please give details		
2	Does the project involve any procedure to the protected animal whilst it is still alive?		
3	Will any part of your project involve the study of animals in their natural habitat?		
	If YES, please give details		
4	Will the project involve the recording of behaviour of animals in a nonnatural setting that is outside the control of the researcher?		
	If YES, please give details		
5	Will your field work involve any direct intervention other than recording the behaviour of the animals available for observation?		
	If YES, please give details		

6	Is the species you plan to research endangered, locally rare or part of a sensitive ecosystem protected by legislation?		
	If YES, please give details		
7	Is there any significant possibility that the welfare of the target species of those sharing the local environment/habitat will be detrimentally affected?		
	If YES, please give details		
8	Is there any significant possibility that the habitat of the animals will be damaged by the project, such that their health and survival will be endangered?		
	If YES, please give details		
9	Will project work involve intervention work in a non-natural setting in relation to invertebrate species other than Octopus vulgaris?		
	If YES, please give details		

Blood Sampling / Human Tissue Analysis

Question		**Yes**	**No**
1	Does your study involve collecting or use of human tissues or fluids? (e.g. collecting urine, saliva, blood or use of cell lines, 'dead' blood)		X
	If YES, please give details		
	If your study involves blood samples or body fluids (e.g. urine, saliva) have you clearly stated in your application that appropriate guidelines are to be followed (e.g. The British Association of Sport and Exercise		

2	Science Physiological Testing Guidelines (2007) or equivalent) and that they are in line with the level of risk?		
	If NO, please explain why not		
3	If your study involves human tissue other than blood and saliva, have you clearly stated in your application that appropriate guidelines are to be followed (e.g. The Human Tissues Act, or equivalent) and that they are in line with level of risk?		
	If NO, please explain why not		

Travel

Question		**Yes**	**No**
1	Does any part of the project require data collection off campus? (e.g. work in the field or community)	X	
	If YES: Data collection will be carried out in the field in Lewisham. Focus groups will be held in school or health service premises alone, time of data collection, unfamiliar or but some home visits may be necessary. hazardous locations, using equipment, the To ensure the researcher's safety, an terrain, violence or aggression from assistant will accompany the researcher others). Outline the precautions that will on any field visits. These will be carried be taken to manage these risks, AS A out during normal working hours and the MINIMUM this must detail how researcher and assistant will be returning researchers would summon assistance in to the hospital base after visits and the an emergency when working off campus. base staff will be informed of where and when the visits will take place. For complex or high risk projects you may wish to complete and upload a separate risk assessment		

2	Does any part of the project involve the researcher travelling outside the UK (or to very remote UK locations)?		X
	If YES: Please give details of where, when and how you will be travelling. For travel to high risk places you may wish to complete and upload a separate risk assessment		
3	Are all travellers aware of contact numbers for emergency assistance when away (e.g. local emergency assistance, ambulance/local hospital/police, insurance helpline [+44 (0) 2071 737797] and CU's 24/7 emergency line [+44 (0) 2476 888555])?		
4	Are there any travel warnings in place advising against all, or essential only travel to the destination? NOTE: Before travel to countries with 'against all travel', or 'essential only' travel warnings, staff must check with Finance to ensure insurance coverage is not affected. Undergraduate projects in high risk destinations will not be approved		
5	Are there increased risks to health and safety related to the destination? e.g. cultural differences, civil unrest, climate, crime, health outbreaks/concerns, and travel arrangements?		
	If YES, please specify		
6	Do all travelling members of the research team have adequate travel insurance?		
7	Please confirm all travelling researchers have been advised to seek medical advice regarding vaccinations, medical conditions etc, from their GP		

Appendix 13: NHS/HRA certification that project is not research

Go straight to content.

MRC Medical Research Council

NHS Health Research Authority

Is my study research?

To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

[redacted]

IRAS Project ID (if available):

195330

You selected:

- **'No'** - Are the participants in your study randomised to different groups?
- **'No'** - Does your study protocol demand changing treatment/ patient care from accepted standards for any of the patients involved?
- **'No'** - Are your findings going to be generalisable?

Your study would NOT be considered Research by the NHS.

You may still need other approvals.

Researchers requiring further advice (e.g. those not confident with the outcome of this tool) should contact their R&D office or sponsor in the first instance, or the HRA to discuss your study. If contacting the HRA for advice, do this by sending an outline of the project (maximum one page), summarising its purpose, methodology, type of participant and planned location as well as a copy of this results page and a summary of the aspects of the decision(s) that you need further advice on to the HRA Queries Line at HRA.Queries@nhs.net.

For more information please visit the Defining Research leaflet

Follow this link to start again.

Print This Page

NOTE: If using Internet Explorer please use browser print function.

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Appendix 14: Lewisham and Greenwich Hospitals NHS Trust audit approval letter

Lewisham and Greenwich NHS
NHS Trust

Clinical Effectiveness Department

1st Floor, Estates Building

University Hospital Lewisham

Tel: 020 8333 3000 ext. 8380/8382

Fax: 020 8333 3384

E-mail: lh.clinicalaudit@nhs.net

10th August 2016

Project Number: 4278

Dear Ms Connor

Project Title: A qualitative investigation of parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support.

Thank you for sending the above Clinical Audit to the Clinical Effectiveness Department, received 08th June 2016.

Your project has been reviewed by the Clinical Audit Review Panel on the 09th August 2016. The purpose of the review is to ensure that all relevant principles of Information and Audit Governance that are applicable to your project are being followed.

We are pleased to inform you that your project has been approved by the Clinical Audit Review Panel and we can confirm that you may now commence this clinical audit.

We would like to take this opportunity to remind you that on completion of your audit, it is mandatory to supply the Clinical Effectiveness Department with a copy of the final report using the Trust Reporting Form which is available on the Trust Intranet.

If you have any questions, please do not hesitate to contact extension 6355 or email Clinical Effectiveness Department at lh.clinicalaudit@nhs.net.

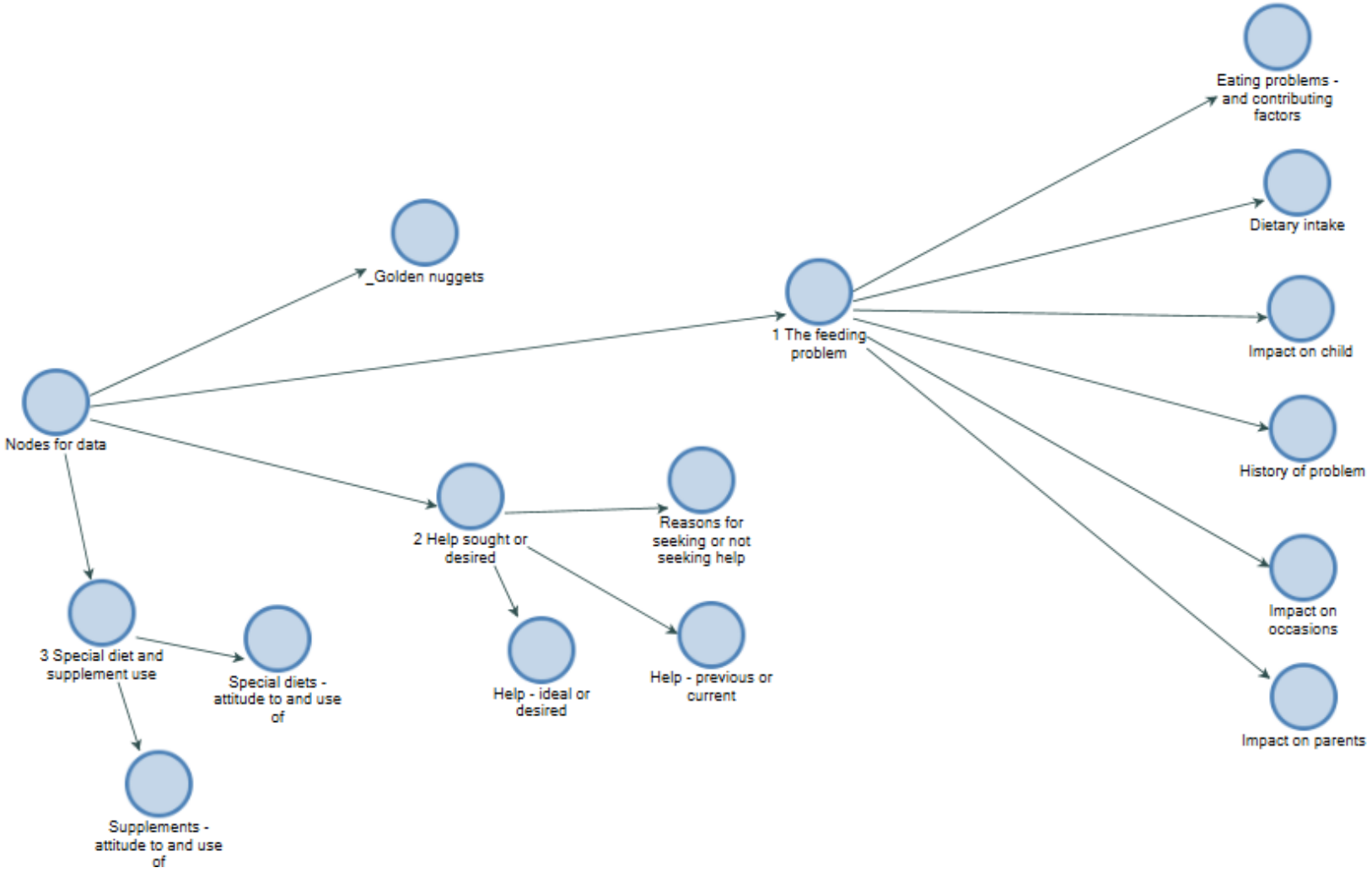
We look forward to hearing from you.

Yours sincerely,

Sarah Goreham

Clinical Effectiveness Facilitator

Appendix 15: Initial theme map



Appendix 16: Member-checking responses

Email sent to all participants on 7/3/17

"I have now finished analysing the interviews I carried out for my research. I used a process called thematic analysis where I look at all the things said in the interviews and in the photos and captions, and find emerging 'themes' – i.e. the key topics that parents told me about.

I would love you to respond to let me know what you think of these themes, whether you think they fit the topic of "parental experiences of eating problems in children and young people with Autism Spectrum Disorder in Lewisham and the professional support they have received and desire"

The list of themes that I have come up with are:

Theme 1: Difficult mealtimes
Subtheme 1a: Unusual eating habits
Subtheme 1b: Trying new food is challenging
Subtheme 1c: Eating problems affect children's health, behaviour, learning and mood
Subtheme 1d: Eating problems impact on parents and families
Theme 2: Unsure when or whether to pursue help
Theme 3: Lowered expectations of parents and professionals
Theme 4: The challenge of finding support
Subtheme 4a: Lack of support
Subtheme 4b: Feeling let down
Theme 5: Services must be easily accessible and supportive
Subtheme 5a: The role of school
Subtheme 5b: A 'super-nanny' service
Subtheme 5c: Group sessions
Subtheme 5d: Online help

I would appreciate it if you respond before 17th March (next Friday) with how you feel about these themes – whether you agree or disagree with them, whether you feel something key is missing from your experience, etc. Even if it is just a sentence that would be very helpful."

Responses received (anonymised)

- Participant 1:
  did not respond to email

- Participant 2 (16/3/17)
  "For me I think you have captured all the key themes, I can certainly resonate with all of them particularly with the themes focusing on difficult mealtimes but that said I agree with all of them. I did not feel at this stage there is anything more that can be added."

- Participant 3 (9/3/17)
  "I agree with your themes and sub themes, overall they pretty much sum up my experience of my children, ASD and food/mealtimes."

- Participant 4 (8/3/17)
  "I agree with these themes. A super nanny service specifically for children with autism sounds really great. Best wishes."

- Participant 5:
  did not respond to email

- Participant 6 (11/3/17)
  "Morning. V good themes. Theme 2 - whether when or where. Knowing where to go for any support is the hardest thing. Thank you for opportunity to join. Regards."

Appendix 17: Participant 1 transcript

¶12: **[00:02:27] Interviewer:** Um, so first of all, can you just tell me about who's in your household?

¶13: **[00:02:31] Participant 1:** Yes, there's three of us. It's, um, uh, Adam [name changed for anonymity] who's Jack's dad.

¶14: **[00:02:35] Interviewer:** Mm hmm.

¶15: **[00:02:35] Participant 1:** And me and Jack.

¶16: **[00:02:37] Interviewer:** Okay and how old is Jack?

¶17: **[00:02:38] Participant 1:** Jack is 12.

¶18: **[00:02:39] Interviewer:** Mm hmm.

¶19: **[00:02:40] Participant 1:** Yeah.

¶20: **[00:02:38] Interviewer:** And, um, can you tell me a bit about him and his eating problems?

¶21: **[00:02:44] Participant 1:** Yeah. Um, **[lip smack]** he, he wasn't diagnosed until he was nine. Um, which, looking back on it, it was sort of pretty obvious but because he was our only child and because we didn't really sort of see the problems as being specific, a specific thing.

¶22: It was sort of a bit of a surprise but looking back on it, he's always had issues with food really. Um, and it's been part of the whole, um, you know, piecing all the sort of clues together. That was quite a big part of it for me definitely.

¶23: **[00:03:16] Interviewer:** Okay. So, what sort of eating problems was that?

¶24: **[00:03:20] Participant 1:** So, when he was a baby, he was absolutely fine. There was no problems because he was breastfed till he was 10 months old and he was fine with food. Um, I think, he then went to nursery, didn't have any problems there. And the food thing started probably become a bit more of an issue when he was about three. I think he started being a bit more sort of fussy.

¶25: And he's always been very controlling. So, at meal times, even when he was two, he would be very controlling about what he was eating and be very sort of vocal about it. So, he would want a particular spoon, for example, or he would want a particular -- He's quite fussy but he liked the bowls that he had and he was quite fussy about which ones he had and I guess that's quite normal for toddlers.

¶26: Um, but, um, I think, really, one of the things that sort of started off the difficulties was using metal cutlery. It's when I identified that he started getting quite sort of the finding meal times more difficult. Because we used to try and introduce him to the table to eat with us, um, say on a Sunday; we always have Sunday lunch because he liked having with us dinner, he enjoyed that.

¶27: But he seemed to have a bit of a problem with being at the table with -- he wouldn't use cutlery, he always used just his hands for everything so, you know. Even for -- I remember him eating ice cream with his hands or, you know, sort of quite **[chuckling]** challenging food that he would prefer to, to use, to not use cutlery. Um, and I guess, the other thing is socially he found food difficult.

¶28: So -- meal times with other people became quite -- he would often retreat from the table if it was a big group. So, uh, family occasions, um, if it was -- if it involved cake he would sort of just about put up with it but otherwise he would find it quite hard to sustain sitting down in a group situation, having conversation or you know just sitting still. He would always retreat as soon as possible.

¶29: **[00:05:24] Interviewer:** Okay and you said, so you said you found it hard

¶30: **[00:05:27] Participant 1:** Mm hmm.

¶31: **[00:05:28] Interviewer:** And he'd retreat. Is there any other sort of **[lip smack]** behaviors that you have around that told you he was finding it hard?

¶32: **[00:05:33] Participant 1:** Um, so he, uh -- I remember going into a restaurant when he was quite little and it was quite noisy and he just ran out and I knew at that point there was something quite wrong. But it was, I think it was maybe the combination of the smell, the noise. He's very sensitive about smells with food.

¶33: And, um, so for example when he goes to other people's houses I think he finds because the smells are different he finds that food quite challenging. Because he picks up on things he's very sort of aware and sort of sensitive. So I've always noticed that a smell can kind of completely throw him you know and sort of make him panic almost you know, it's kind of --

¶34: **[00:06:23] Interviewer:** And when he panics what, what --

¶35: **[00:06:24] Participant 1:** So he'd run off generally.

¶36: **[00:06:24] Interviewer:** Okay.

¶37: **[00:06:24] Participant 1:** Yeah, yeah.

¶38: **[00:06:27] Interviewer:** Just escape, escape.

¶39: **[00:06:28] Participant 1:** Yeah, yeah get out you know, uh.

¶40: **[00:06:30] Interviewer:** Okay and does he, does he get upset in other ways?

¶41: **[00:06:34] Participant 1:** Uh, yeah I mean he finds he, he finds social things difficult. So if he's, he's come, coming into a room with lots of people he'll find that really difficult. If the people are looking at him more or, um, he's very sort of, uh, it's kind of like shyness but then he can also be very unshy.

¶42: So it's sort of, um, you know sometimes he quite likes attention. So sort of it's the -- he doesn't like going into group situations at all, he finds that really hard whether it involves food or not yeah.

¶43: **[00:07:05] Interviewer:** Okay and you've shared some great photos with me thank you.

¶44: **[00:07:07] Participant 1:** Yeah.

¶45: **[00:07:08] Interviewer:** Um so do you want to tell me a bit more about, sort of these photos?

¶46: **[00:07:13] Participant 1:** Yeah.

¶147: **[00:07:13] Interviewer:** Because I asked you to choose photos that told me a bit about your child's eating problems and how they affect him and you and the rest of the family so open up **[inaudible 00:07:23]**

¶148: **[00:07:23] Participant 1:** Yeah, so okay. So, uh, the first one is Parmesan container that's metal and, um, Jack's dad really loves food and is a bit obsessive about food. And has always tried to involve Jack with his cooking and so Jack learned how to cook pesto when he was very little. And he quite enjoyed the whole cooking process. And he, he does like pasta and he likes the sort of **--**

¶149: He likes the smell of the basil I think the kind of mixing process and all that stuff. And so he, he you know he really loves Parmesan so we always, we had it quite often when he was little. And we always use this metal dish and he used to get really upset with the noise of the metal, um, the metal spoon scraping the bottom of the dish.

¶150: And so although he loved pasta he'd always kind of have this little sort of upset around the cheese. Which I just didn't, I didn't work out for ages. And then I realized it was a lot to do with the noise and he also -- When I asked him about it he also sort of did admit that the noise of cutlery on china was also difficult for him.

¶151: And I don't think he'd even thought about it but it became pretty obvious that that was a kind of bit of a problem. And so we changed the spoon and, and now it's fine and he, he quite likes it and he likes the wooden spoon. Um, and he'd prefer to use wooden cutlery if he could **[chuckles]**, you know all the time I think.. so.

¶152: **[00:08:53] Interviewer:** So when, so when you used to have the, uh, metal spoon to do --

¶153: **[00:08:55] Participant 1:** Yeah.

¶154: **[00:08:55] Interviewer:** What, what sort of affected it have when you were using it? He just, it just sort of upset him or?

¶55: **[00:09:00] Participant 1:** Yeah, I think it was more, it was he couldn't relax so it was more like in, in a mealtime he sort of after you had make the food he'd been involved in making it and all the rest of it and then sit down and try to eat it. And as soon as there's be an, a noise it would just actually make him want to leave or not be able to cope with it. So he would jettison the meal and not eat.

¶56: **[00:09:22] Interviewer:** Okay.

¶57: **[00:09:22] Participant 1:** Because it would put him off to the extent that he couldn't just go, "Oh, that was a bit annoying," you know. Um, it would just sort of just send him off so yeah.

¶58: **[00:09:32] Interviewer:** Okay.

¶59: **[00:09:33] Participant 1:** Um, so shall I go on to the next one?

¶60: **[00:09:35] Interviewer:** Yes please do, oh, I knew you'll do that

¶61: **[00:09:38] Participant 1:** Um, yeah so this is so Jack's always liked to be, uh, when he's eating he's always liked to have, have a distraction. When he was about three he used to go to child minder, um, and she used to have her telly on all the time which I used to sort of worry about a little bit. But he, he really got used to eating in front of the telly and he was you know I found it quite hard especially when we went --

¶62: Say for example he's got cousins that we, we go on holiday with sometimes. And he would want to watch telly and they're not really allowed to watch telly at mealtimes so it became bit of a thing. And so, we kind of booought -- so we sort of made -- we sort of got him to look at books instead of the TV.

¶63: And he -- his first thing he does at breakfast every morning is to he'll sit down but he will have a comic whilst he's eating and that sort of a very normal thing for him.

¶64: **[00:10:30] Interviewer:** Mm hmm.

¶65: **[00:10:30] Participant 1:** And something that he does every day if he can, um, and yeah, it's just sort of habit.

¶66: And he also quite likes eating. If I say to him, um, uh, “You’re eating on yourse -- by yourself this evening because dad is going to be late coming home from work.” He, he quite likes that because he likes having dinner on, on his own, he prefer in a way, because it’s less challenging food and he’s got his books and he can sort of, yeah.

¶67: **[00:10:57] Interviewer:** Okay. And if he did not have his books would he?

¶68: **[00:10:58] Participant 1:** He would -- I mean sometimes I try and sit with him and just have a conversation, but he’s not very good at it, um **[laughs]**.

¶69: **[00:11:05] Interviewer:** Okay, he'll still eat if you don't, if the books aren’t there or?

¶70: **[00:11:09] Participant 1:** Um -

¶71: **[00:11:10] Interviewer:** Does it vary?

¶72: **[00:11:12] Participant 1:** Would he still eat? Yeah, yes, probably I think he would because he’s now at a stage where physically he needs food a lot more.

¶73: **[00:11:19] Interviewer:** Mm hmm.

¶74: **[00:11:20] Participant 1:** So it’s a little bit easier now actually.

¶75: **[00:11:21] Interviewer:** Mm hmm.

¶76: **[00:11:21] Participant 1:** Because he is just hungry, um, which is great **[laughs]**. So I think he probably would but he might not sit down, I mean, sometimes he stands up, he won’t even sit -- you know sometimes prefers just to -- he'd be more likely to stand up and eat.

¶77: **[00:11:36] Interviewer:** Okay.

¶78: **[00:11:37] Participant 1:** Yeah or get up eat around, yeah.

¶79: Um, so yeah, this, this is a picture of a meal that he prepared, that he get cooked himself. We did a sort of little kind of game with his cousins where they all had to cook a meal out of some sort of basic ingredients. And he cooked

something which was weird because he, he, he doesn't really like salad or salad dressing but he cooked it.

¶80: He, he prepared this quite elaborate salad dressing. He was very specific about the flavors and you know spent a long time kind of making it. And then he ate it afterwards which was a bit of a sort of a strange thing as well because I never seen him eat salad dressing or salad, but he really enjoys it. And if he's in control, he's happy. And if -- it's all about control with him.

¶81: If he can, um, **[lip smack]** take part in preparing the food, uh, and choosing it then he's okay, he's relaxed. But if it gets presented to him and it is a surprise, it's a real, real problem. Uh, so the same with the packed lunch in a way. He, he, he likes food. The packed lunch box is comp, compartmentalised so he likes the sort of separation of different food types.

¶82: He thinks about food in quite a scientific way.. that he knows he needs his different elements. Um, **[lip smack]** and he is quite private about it. So at the school I've seen him once, at his primary school as -- I happened to seen him in a dinner hall and he had his packed lunch box underneath the table and he was eating in a very sort of secretive way. Um, and that's what I think what he did every day.

¶83: He had the sort of system that he would have his packed lunch box at his lap and then eat each food one at a time, quite sort of systematically. Um, and you know it's, it's, it's okay because he's in control again; it's like what he can choose what's he going to eat and when. And um, yeah, it sort of works, but as soon as there's any kind of --

¶84: You know if I, if I asked him to have a school dinner, he would find that really difficult. He wouldn't want to join in with everyone else. You know sort of he, he couldn't do that, we'll it'd upset him and he wouldn't eat. He would choose not to eat.

¶85: **[00:13:52] Interviewer:** So I was looking at it and then I, I noticed, you know its separated is that normal?

¶86: **[00:13:55] Participant 1:** Yeah.

¶87: **[00:13:55] Interviewer:** Does it have to be separated?

¶88: **[00:13:58] Participant 1:** Uh, it doesn't have to be.

¶89: **[00:13:58] Interviewer:** It doesn't have to be.

¶90: **[00:13:59] Participant 1:** But it really helps, you know he really likes it if it is -- and he also , yeah, he likes to sort of, um, to think about it in different food groups, yeah.

¶91: **[00:14:07] Interviewer:** Okay and does he, does he have mixed foods? Because that also, looks like -- it's not sort of ...

¶92: **[00:14:11] Participant 1:** He doesn't like sandwiches.

¶93: **[00:14:13] Interviewer:** No, he doesn't like sandwiches.

¶94: **[00:14:14] Participant 1:** No, so I mean, funny enough I did buy him once a sandwich that was a specific sandwich that was salt beef, gurkins, mustard, lettuce and it was -- he really enjoyed it and that's the only sandwich he will eat.

¶95: **[00:14:27] Interviewer:** Okay.

¶96: **[00:14:27] Participant 1:** Because he did try it and he really liked it. Um, same with hamburgers, he sort of -- first of all, he will only have a hamburger with nothing else in it and then he realised that actually ketchup, and you know pickles and mustard was really nice. So he sort of get used to it and now he's sort of into that.

¶97: So mixed food is beginning to -- he is beginning to kind of trying to get him to sort of enjoy the flavours because he's got this palate that is very sort of sensitive and, and you know in a way of getting him to enjoy the mixture of flavours, but he's very funny about sandwiches.

¶98: **[00:15:05] Interviewer:** Okay and is that, uh, -- is there, um, a variety of different things he'll put in the lunch box?

¶99: **[00:15:10] Participant 1:** He doesn't, uh, variety -- yeah, not much variety. But I put in, you know a different biscuit or a different piece of fruit. Like today he had grapes -- today he had grapes, the same pea tops which he really likes,

which are like a lot lettuce type of thing. And then he had, um, I can't remember what he had for the sort of savoury thing. I think he had, um, peanut butter in rice cakes again and --

¶100: **[00:15:37] Interviewer:** Okay, is that what that is? Is that peanut butter?

¶101: **[00:15:38] Participant 1:** Yeah, yeah, probably and some fruits probably.

¶102: **[00:15:40] Interviewer:** Okay and is that -- is that fruit juice?

¶103: **[00:15:41] Participant 1:** And that's a fruit juice, yeah, that he doesn't like having -- we, I used to buy him cartons and then he got quite self-conscious about the brand of, of juice. Like it might be too babyish or it might say organic and it's a bit embarrassing at school or -- So he prefers it if I just put, uh, a sort of a juice into another bottle so it's just sort of, um, you know non-specific.

¶104: **[00:16:07] Interviewer:** Okay.

¶105: **[00:16:07] Participant 1:** He doesn't mind that. And he really loves -- he's a, he's a, he's a bit of a sugar -- he really likes sugar, so it's really easy for him to eat fruit. And he's -- that's when he was a kid that was mostly what he ate really. Um, and it's not so easy to get him to eat carbohydrate, um, he does also that meat, uh, but he doesn't have it for lunch.

¶106: **[00:16:28] Interviewer:** You said that, um, that came home uneaten that day.

¶107: **[00:16:31] Participant 1:** Yeah, yeah.

¶108: **[00:16:32] Interviewer:** So that, is that something that happens?

¶109: **[00:16:34] Participant 1:** Yeah, so that was -- um, I do, it doesn't happen that often thank goodness. But I think, uh, uh, it has to do with the sort of, um, busyness of the school dining hall that he got there a little bit late, there was nowhere to seat that he felt was appropriate. And he -- it was all sort of too stressful so he just said, "Okay, I'm not, I'm not going to do this, I'm going to," --

¶110: Um, and he doesn't realise when he's hungry. You know he doesn't have that sort of -- most people in that situation will be you know, "That's annoying

but I'll have to eat." But he could quite easily miss a meal and not understand that he's in a bad mood because he's missed a meal and that's always been his problem really, um.

¶111: **[00:17:15] Interviewer:** And how does that affect him when he just need -- is it maybe --

¶112: **[00:17:19] Participant 1:** He gets quite bad, um. I mean, he -- yesterday we went to his cousin's house for her birthday and he wouldn't eat the very nice lunch that they put on. So, I gave an alternative, took an alternative with me, but he didn't eat very much of that and he then eat sugar. He ate like -- they had some sweeties and stuff and he ate that. And he got -- he has sort of these crashes where he just was on the floor kind of practically asleep.

¶113: Because he gets these real kind of you know sugar and then crashes and doesn't have anything to sort of, you know no energy. Um, and he gets that quite often because he loves sugar so he just craves it and then, um, it gives him a bit of energy and then, and then it sort of you know, makes him feel worse, mm hmm.

¶114: **[00:18:07] Interviewer:** Mm hmm. Does, uh, does his eating issues affect him at all like with his growth or anything? Is he, is he underweight or overweight or?

¶115: **[00:18:14] Participant 1:** I think he's, he's quite little. But I think, thank goodness, I think he seems quite fairly healthy.

¶116: **[00:18:18] Interviewer:** Okay.

¶117: **[00:18:19] Participant 1:** Because we sort of found ways around it and he does -- you know he is definitely someone who I sort of encourage him to eat snacks because that's what he, that's the only way he'll really eat quan -- you know he won't eat a a big meal, he'll, he'll -- So I do give him when he comes home from school, fortunately, I can --

¶118: I am at home now so I can actually make sure he eats something at 3:30 every day as well as lunch. Yeah. So he seems to be, health-wise, he seems to

be okay and he's quite little but I think he's sort of you know nothing to worry about.

¶119: **[00:18:50] Interviewer:** Ok, excellent

¶120: **[00:18:58] Participant 1:** Um, so the final picture it was one -- it's a holiday photo that, um, sort of sums up how you know on holiday, you kind of want meal times are real sort of treat and you want, you know to enjoy it.

¶121: And often you just can really and it does have a bit of an impact on our -- you know relax -- relaxing time. And so this is his cousins, two of his cousins behind. And he would find it very hard to sit on a table with them even though he knows them really well. And, um, yeah, it's just he loves Italian, we were in Italy, he loves Italian.

¶122: But again, it's because there's a bit of an element of risk when he's ordering food from the menu because they can say it one thing. Like he ordered -- they had really delicious food in this place - and he ordered some Spaghetti Bolognese or Spaghetti Ragu which he loves, but it was -- it was a different type of meat and I think they probably used some other, maybe, maybe not have been beef, it may have pork in it as well. And so also and so it tasted different and he -- it really threw him completely because he had -- It's a control thing again. He'd ordered something but it wasn't what he expected and it upset him. So it was problematic, mm hmm.

¶123: **[00:20:12] Interviewer:** Okay. And, what -- Can he tell you what, um, what upsets him about sitting with everyone else?

¶124: **[00:20:23] Participant 1:** Not really, he can't articulate it. I don't think he really knows.

¶125: **[00:20:26] Interviewer:** No.

¶126: **[00:20:26] Participant 1:** No. I mean, uh, on this holiday a sort of -- sort of there were lots of people that we knew there and he would come and sit down for a bit and then he would -- I always took a book with us or you know, I'd have, yeah -- usually he had a book so he could just sit down and read.

¶127: But even that sometimes it's too difficult and he just used to run away. And it was -- He stays near-ish so we wouldn't get too stressed but it was, you know, he wouldn't physically sit down.

¶128: **[00:20:59] Interviewer:** Okay. Has that always been the case when he was younger or -- ?

¶129: **[00:21:04] Participant 1:** Uh, yeah, yeah.

¶130: **[00:21:06] Interviewer:** Okay.

¶131: **[00:21:07] Participant 1:** Yeah. He often comments on, uh, these, these cousins, so, he doesn't see so often but his other cousins, um, he sees quite a lot and he often comments on the noise they make when they eat that he finds difficult. So, he -- although he eats with them a lot, if there's anyone in the world he eats with it's his -- these two cousins but he sometimes just finds -- he sorts of --

¶132: He made a comment recently to me about how them, one of them might eat with her mouth open or -- you know. So, he's got this thing about noise as well that it can be off putting.

¶133: **[00:21:43] Interviewer:** And does that affect him at school as well?

¶134: **[00:21:46] Participant 1:** I think it must do, yeah. I think, the school thing and primary school it was definitely the smells. But I think it was also the noise factor just because there's lots of people in one room. But the same -- I mean I used to go into that dinner hall **[chuckles]** sort of I find, find the smell a bit much you know -- it was kind of that school dinner smell is quite lingering, you know. Um, and he just found it completely overpowering.

¶135: **[00:22:07] Interviewer:** Yeah, that was -- They're quite noisy as well.

¶136: **[00:22:09] Participant 1:** Yeah, and sort of clatter.

¶137: **[00:22:10] Interviewer:** Yeah.

¶138: **[00:22:10] Participant 1:** And it's this cutlery again that's just sort of -- You know how those, there's with metal cutlery trays --

¶139: **[00:22:15] Interviewer:** Mm hmm.

¶140: **[00:22:16] Participant 1:** Which they people throw cutlery into the -- when it's dirty. And that kind of noise I think is just sort of --

¶141: **[00:22:22] Interviewer:** Yeah.

¶142: **[00:22:23] Participant 1:** Makes him quite edgy.

¶143: **[00:22:25] Interviewer:** Okay.

¶144: **[00:22:26] Participant 1:** Yeah.

¶145: **[00:22:26] Interviewer:** Um, mm hmm, and, um, and how do you think it's affected -- So, you're saying as far as, um, he's concerned and it can affect his mood and maybe, you know, at school as well, it can affect him. How does that affect you all as a sort of family unit or do you think you do things differently because of his eating issues?

¶146: **[00:22:47] Participant 1:** Yeah. I think when -- when he was -- Before he was diagnosed, I very much, I used to get very upset with my partner Bob, um, talking about food a lot because I thought that the talk of the food was sort of, uh, having was the, was sort of making Jack behave in a certain way. And I'd wanted to sort of try and to sort of not talk about it so much, not make it such a big deal. So that it wasn't the centre of attention all the time and I think -- So, I sort of blamed Bob for it a bit, which I think was unfair from hindsight, you know, because his love of food it's, there's nothing wrong with it you know. Um, but I think you sort of look for what you're doing wrong yourself. So, a lot of the time I think I sort of thought we were doing something wrong. Or, um, you know, look at other kids who's sort of merrily eating and think, "What -- Why have we -- Where have we gone so wrong with it?" You know, so I think lot of the time. The first thing you do is sort of assume that you are making mistakes somehow, or you're doing something wrong. Um, and I think that did burden us quite a lot for many years really. So, I think, before -- as soon as he was diagnosed, I think we began to sort of be able to be a bit more confident about seeing the problem rather than looking at ourselves. So, you know, the blame or whatever yeah, um.

¶147: **[00:24:12] Interviewer:** And, when, and when was it at its worst, his eating issues? Do you think they were -- they've sort of stayed about the same or do you think they were worse when he was younger?

¶148: **[00:24:20] Participant 1:** I think they've got better, thank goodness. I think it was worst when he was about eight probably. Because I think it was his age where they need to eat quite a lot. And he, was often sort of hungry at school so not being able to work properly and getting quite agitated. And I think the sort of thing about, uh, you know it's -- maybe it was difficult when he was young as well - but he does ... sort of need sugar, which is a definite sort of, um, you know, it's his body telling him he needs energy, I think. And it's, it does have a bad impact on him and I don't think I was very like I used to give him fruit juice for example when he was quite young and I think that was probably not a very good thing to do. If I'd been you know -- I think I encouraged him almost to use sugar as a sort of energy thing.

¶149: Um and so when he was eight that was quite bad so he got really obsessed with sweets and he used to really just hanker after sweets all the time. It was quite difficult because I didn't really want to ban sweets because, um, I, I sort of feel like if you ban foods you're kind of drawing attention to them more, and somehow it can have the worst, you know it can have the opposite effect. But I was quite, I was quite worried that you know there would be this thing every time people would have a birthday his primary school would give out sweets. So it would be that this awful thing at end of day where he would just eat loads of sweets and then get in a really bad mood and then not eat dinner you know this kind of thing.

¶150: So I think it has got better since then he doesn't, he's not so obsessive about sweets now. He has a bit more control over his own money, so if he wants at the weekend he can go and buy sweets. And he's quite sensible really you know he doesn't, doesn't go mad so it's fine.

¶151: **[00:26:10] Interviewer:** And what's helped with sort of moving him along with his eating habit? Is it have you had any external help or is it all-?

¶152: **[00:26:16] Participant 1:** The only thing we had was that before he was diagnosed we had, um, somebody looking at at him, uh, not -- what was it, uh, I can't remember the name of the title of the profession someone who's looking at the way he's holding his cutlery and --

¶153: **[00:26:32] Interviewer:** Occupational therapist?

¶154: **[00:26:32] Participant 1:** Occupational therapist, yeah exactly. And she, she sort of looked because we were concerned about this cutlery thing. She looked at the way he was holding it and she did, she did sort of think that there might have been a sort of slight issue with him not being very capable with holding them the cutlery. So we looked into buying some different types of knives and forks and stuff, but we didn't ever do it and actually I think there is an element that he, the coordination is quite difficult. But I don't, so that was sort of you know we kind of did talk to someone about it but we never really got anywhere with that.

¶155: **[00:27:08] Interviewer:** And how old was he then?

¶156: **[00:27:10] Participant 1:** I think he was about nine.

¶157: **[00:27:11] Interviewer:** About nine.

¶158: **[00:27:11] Participant 1:** Yeah, yeah.

¶159: **[00:27:11] Interviewer:** Okay and then did you seek out that by yourselves or was it somebody else?

¶160: **[00:27:15] Participant 1:** No, that was, that was the first stage from some -- the school contacted, uh, us about it and asked us to go and see a GP. We went to a GP and then we got a referral to, um, CAMHS and they, the occupational therapist was the first thing we did before diagnosis yes, yeah.

¶161: **[00:27:33] Interviewer:** Okay, was that part of the social communication?

¶162: **[00:27:40] Participant 1:** yeah.

¶163: **[00:27:33] Interviewer: ...** Okay, okay, um, okay. And before that when we was younger was there any -- had you sought help?

¶164: **[00:27:44] Participant 1:** No.

¶165: **[00:27:45] Interviewer:** You seem, you seem like you're quite aware that there was or some issues around his eating but you were --

¶166: **[00:27:49] Participant 1:** Yeah, I didn't ever think, um, I think I was too busy blaming ourselves so I didn't ever think it was someone -- anyone else could help **[laughs]**. Um, so I didn't know, I didn't, yeah

¶167: **[00:28:01] Interviewer:** And what sort of things, um --So thinking back what sort of help would you have liked to have received or do you feel like you weren't really looking for help at that stage?

¶168: **[00:28:14] Participant 1:** I think I would have liked the school to have been a little more on it with watching what was happening at lunch hour. Because he didn't, he didn't have packed lunch until he was about, I think it was when he was about eight. I suddenly sort of realised that he wasn't, he hadn't been eating. And I think I would have liked a bit more support, support from the school just to sort of check what was going on at lunch hour. I know there's a lot to do because there are so many kids but it would have helped if we'd known what exactly he was eating, um.

¶169: **[00:28:44] Interviewer:** Okay, had they not picked up on it at all?

¶170: **[00:28:45] Participant 1:** No, no.

¶171: **[00:28:46] Interviewer:** No. And was it them that picked up on the social communication issues? Okay so they noticed that --

¶172: **[00:28:51] Participant 1:** Yeah, yeah so they picked it up in the classroom just because it's you know -- lunch hour was kind of I guess the teachers aren't often involved. There was no observation at lunch hour and I think there should have been really. Because then it may have even been picked up before the classroom stuff.

¶173: **[00:29:08] Interviewer:** Okay and now looking at it all, is there any sort of help that you think would be useful with his eating now and ongoing or-?

¶174: **[00:29:18] Participant 1:** Um, it's a really difficult one.

¶175: **[00:29:19] Interviewer:** Like in an ideal world without the constraints of the NHS

¶176: **[00:29:21] Participant 1:** Yeah, yeah.

¶177: **[00:29:25] Interviewer:** And what would it look like if there was sort of an ideal sort of help?

¶178: **[00:29:31] Participant 1:** Oh, I mean we did -- they do get -- well I did, I do think it's important is that they learn about nutrition at school. I do think that Jack has learned quite a lot at school because he likes that kind of scientific aspect of food. And I do think he's been taught quite well about nutrition, um. But I suppose I suppose the, what I don't think it's quite so important at school is the sort of social communication when you are in a dinner hall ... I think that because dinners at school are all about just getting the kids in and out and it's such a sort of rush. And it's not ever kind of seen as a sort of place where people need to learn how to socialise or learn how to, um, be considerate of others or learn how to clear up after themselves or all that stuff. And maybe in an ideal world schools would have more time to actually sit in, in groups, talk whilst they are eating, clear up after themselves, you know just be a bit more sort of -- in order to give themselves life skills for later on, you know.

¶179: **[00:30:42] Interviewer:** Mm hmm.

¶180: **[00:30:42] Participant 1:** I mean that would be really nice but, um.

¶181: **[00:30:47] Interviewer:** Could they modify it in any other way to help him do you think?

¶182: **[00:30:50] Participant 1:** Uh.

¶183: **[00:30:51] Interviewer:** At the dinner?

¶184: **[00:30:52] Participant 1:** They need, they need more space and they need more -- I mean it's sort of crowded and loud and, um, he goes to a school that is

you know, there is a lot of discipline issues and there's lots of noise and there's lots of noisy kids and, uh, it's just not that realistic you know, um.

¶185: **[00:31:11] Interviewer:** Are there other options for places to eat or is it all --

¶186: **[00:31:13] Participant 1:** It's all in the school and, uh, you know, uh, I think there's a lot of -- I think that eating -- unfortunately a lot of the kids in the school really, don't have great diets.

¶187: **[00:31:26] Interviewer:** Mm-hmm.

¶188: **[00:31:26] Participant 1:** And it kind of upsets me a bit like going and eating a pack of crisps for breakfast and then there's chicken shops outside the school which are you know hugely used after 3:30 they are full of kids.

¶189: **[00:31:38] Interviewer:** Mm-hmm.

¶190: **[00:31:38] Participant 1:** So there's a culture of that that somehow I, I, I suppose in ideal world I would like the health service and the school could sort of work together to try and improve that somehow. That, you know it would be great wouldn't it? **[laughs]**

¶191: **[00:31:52] Interviewer:** Yeah,

¶192: **[00:31:53] Participant 1:** Because it's all about learning how to look after yourself as a --

¶193: **[00:31:56] Interviewer:** Yeah.

¶194: **[00:31:57] Participant 1:** You know for later on.

¶195: **[00:31:58] Interviewer:** Life skills.

¶196: **[00:31:58] Participant 1:** You know it's like --

¶197: **[00:32:00] Participant 1:** Absolutely.

¶198: **[00:32:01] Participant 1:** It, it's, it's a bit like learning how to do sport or sort of look after yourself physically which they are really good at actually they are really good at sort of because Jack hates sport but they are really good at

making sure he's keeping active and fit and allowing him to compete with himself rather than other people.

¶199: **[00:32:18] Interviewer:** Well that's good, that's interesting yeah.

¶200: **[00:32:19] Participant 1:** Which is great.

¶201: **[00:32:20] Interviewer:** Yeah.

¶202: **[00:32:20] Participant 1:** But you know the food thing just doesn't-- and they serve really quite bad food at the school you know, Jack's talking about this water they serve that has -- it's sort of like a sort of sweetened water that everyone drinks.

¶203: **[00:32:31] Interviewer:** Mm-hmm.

¶204: **[00:32:31] Participant 1:** It's just not great. You know it's just the water fountains are unavailable because people kind of you know are sort of get, um, you know broken and stuff. And so there's a sort of culture of just allowing kids to eat badly, which you know and I don't know whether Jack has that --

¶205: Um, um maybe I'm talking more about people generally but I think that would help him if they, if they had a quieter calmer, um, sort of way of eating it would be good for him.

¶206: **[00:33:01] Interviewer:** Okay.

¶207: **[00:33:02] Participant 1:** Mm hmm.

¶208: **[00:33:02] Interviewer:** But is it **--** but that generally their curriculum around food has been good, does he do cooking?

¶209: **[00:33:05] Participant 1:** Yeah, yeah they do, yeah they have done cooking and he's, but he's found that quite difficult because he's a perfectionist. You know he's got such strong kind of ideas about how things should be that I think he found it quite hard because he's not actually a brilliant cook, but he sort of, in his head he is so.

¶210: **[00:33:24] Interviewer:** Mm hmm.

¶211: **[00:33:24] Participant 1:** I think he found that quite difficult but I think it's great that they do that you know I think that's brilliant.

¶212: **[00:33:31] Interviewer:** Fantastic.

¶213: **[00:33:31] Participant 1:** I think that helps but I think in terms of the NHS, I don't know what else, how else they -- like I could never been to the doctor and said, "I am worried about Jack's eating." Um, because of, you know he's never been worryingly underweight or anything like that.

¶214: **[00:33:43] Interviewer:** Mm-hmm.

¶215: **[00:33:43] Participant 1:** Um, uh, I'm going to think certainly I was aware, I'm sort of aware that you know -- there was one period where he was sort of regurgitating food a lot. Um, I think it was when he was about eight and he'd sort of, he was often, I could smell he had sort of been sick slightly after food and I was well sort of I was sort of feeling like this could maybe be the beginnings of some sort of eating disorder or you know whatever and I was certainly aware of that, um and then just forgotten it until now so obviously it sort of settled down but I do think the information about that is probably really key for kids of Jack's age you know he's 12.

¶216: **[00:34:23] Interviewer:** Mm-hmm.

¶217: **[00:34:24] Participant 1:** And I would like it if I went to the doctor with any concerns that they would take that seriously.

¶218: **[00:34:28] Interviewer:** Yeah, and did you find that learning about his diagnosis -- that when he got his diagnosis --

¶219: **[00:34:35] Participant 1:** Mm mm.

¶220: **[00:34:36] Interviewer:** Learning more about autistic spectrum helps sort of put the --

¶221: **[00:34:40] Participant 1:** Yeah.

¶222: **[00:34:40] Interviewer:** Pieces of the puzzle together with the --

¶223: **[00:34:42] Participant 1:** Yeah.

¶224: **[00:34:41] Interviewer:** Eating? yeah.

¶225: **[00:34:42] Participant 1:** Yeah, definitely.

¶226: **[00:34:43] Interviewer:** What sort of support did you get when he was diagnosed?

¶227: **[00:34:45] Participant 1:** Um, I was referred to a, to Drumbeat, do, do are you aware of Drumbeat?

¶228: **[00:34:50] Interviewer:** Yeah.

¶229: **[00:34:51] Participant 1:** You must be, and so they do a six week course for parents with recently diagnosed kids. So that was a sort of, um, once a week there's a group session and I learned a huge amount to sort of --

¶230: **[00:35:03] Interviewer:** It was specifically for his age group as well, yeah, yeah.

¶231: **[00:35:04] Participant 1:** It was, yeah. So it was recently just diagnosed but between the ages of nine and 12 or nine and 11 or something. So, so the other, um, people that had kids who were also just about to start secondary school and you know one of the things we discussed is, was mealtimes yeah, so yeah.

¶232: **[00:35:22] Interviewer:** Okay. What sort of things did they discuss in there that you found useful?

¶233: **[00:35:26] Participant 1:** Um, about foods specifically yeah.

¶234: **[00:35:32] Interviewer:** Yeah, I suppose I'm trying to sort of put the pieces together. How did you know the sort of things that you learn in that group.

¶235: **[00:35:39] Participant 1:** Yeah.

¶236: **[00:35:40] Interviewer:** Yeah, how did they sort of help you to sort of see his feeding different?

¶237: **[00:35:43] Participant 1:** Right, I think probably I underestimated the importance of the sensory issues that Jack had. And because I was told very

sort of because we were sort of talked about the, the, the sensory issues in a sort of slightly different -- you know it was sort of talked about. I kind of it made me realize just how important it was and I had underestimated that, um, as a thing.

¶238: So the noise, the smells the fact that he's got this sort of palate that's sort of very sensitive, um, it all I think that's what made me realise and sort of definitely helped yeah.

¶239: **[00:36:27] Interviewer:** Mm hmm. Um, mm hmm, okay. So I think, oh, oh, I think -- So you told me a lot about his eating problems which was you know really interesting and you've brought us some great photos along. And we talked a bit about sort of professional help, um, and it sounds like you know you feel like you sort of muddled through it quite well.

¶240: **[00:36:53] Participant 1:** Mm hmm.

¶241: **[00:36:54] Interviewer:** And, and maybe having some of that education around autism has helped you to sort of frame his eating problems on a slightly different way.

¶242: **[00:37:01] Participant 1:** Yeah.

¶243: **[00:37:01] Interviewer:** Which then helps sort of see things through his eyes maybe. Is there anything else that you want to tell me about his eating problems or just generally?

¶244: **[00:37:13] Participant 1:** No, I can't think of anything no, no.

Appendix 18: Participant 2 transcript

[00:02:38] Interviewer: Let's get started just with some easy things. So, could you tell me who's-who's in your household, who other than you?

[00:02:46] Becky: So, um, my partner Scott, um, and obviously Ben and my daughter Bea.

[00:02:52] Interviewer: Okay so there's four of you. And tell me a bit about your child who has autism.

[00:02:58] Becky: So Ben, he was diagnosed when he was, um-um, four. Um, so we just um, we had our concerns at first, he had sort of, uh well, he had a quite a delay in his speech. Anyway, we had been referred a pediatrician and we thought we'd wait, at that point it was a bit early for diagnosis, wait for another year see how he progressed at nursery and his speech, etc. So, um - we did, and um, whilst he did progress, he was quite a bit behind the other children and took him a long time to, um, settle in at nursery, interacting with the other children etc. um so when we went back to the pediatrician she diagnosed him, um, with ASD.

Um so, in terms - in terms of Ben generally, um, I mean - he's at school now and he's now really just starting to sort of, um, interact properly with the other children. But he is very settled, he's quite a happy child um yeah, he's, uh he is doing well, and he's actually probably at the moment just a year below what he should be. He should be in year two, he's actually, um - and it's our choice and the school's choice - to have to, um, put him back in year, he's back in year one. He seems to be much more settled and is able to have more friendships, etc. He seems to be on a more emotional sort of level than his proper cohort. You know, he-he's quite a sociable child really. A lot of people, actually when I tell them he has autism, um, are actually quite surprised when I tell them, because I think everyone has their views, or conceptions, each level and where your children or child is, so, um it can vary.

He will touch people, give contact--eye contact, and people assume with autism that they won't look at you, etc., but with Ben that's not the case at all. He does

like to have a routine, but when the routine changes he can cope with it but you have to explain to him before, that this is gonna happen. He likes to know whats going to happen, just to prepare him really. But generally he copes quite well with changes.

[00:05:32] Interviewer: That's good.

[00:05:53] Becky: He does have this repetitive way; he'll run up and down - I know some children flap or things - whereas Ben will run up and down, specifically when he gets excited, I don't know if its to release some energy, but he'll sort of run up and down and keep doing it.

And then obviously with his eating... so.. as a baby, he was absolutely fine when eating, I think he got to about, um, 18 months, just coming up to Christmas he was quite poorly, had a really horrible virus. And obviously his appetite just completely went. So we just put it down to him being unwell. But after that he just never seemed to get it back. So when I-I had Ben and after a year I went back to work and my, um, in-laws used to look after him, and they use to make me meals so that when I got home from work it would be easy to-- and he would eat fish, casserole, he would try anything. Let's say, then he got about 18 months and was poorly and then after that he stopped eating, I know he use to eat this fish dish and he stopped eating that. And then gradually he stopped eating a lot of things, then we were sort of - our choices had become quite restricted. And it never ever improved, in fact it got worse and that is how it is today really. In terms of, he'll only eat a handful of things, different things, so that can be quite tricky really.

[00:07:32] Interviewer: Okay, yeah. Thank you. You sent me - um, you sent me the photos too, that's really great. I'm just having a look at some of those photos now. So, the first one you sent me was a picture of the main foods that Ben eats. And that's Wotsits, then a Kidolicious smoothy melt, so are those like fruit - um, fruit things.

[00:07:44] Becky: Yes

[00:07:32] Interviewer: And then Nutella and bread.

[00:07:54] Becky: Yes. Actually,that is massive-- yeah, Nutella is a big thing.

[00:07:59] Interviewer: Does he have it with the bread or--?

[00:08:04] Becky: Yeah, he does, on a typical day, at the moment in the mornings normally its always toast with Nutella, it has to be almost... at the moment it has to be almost cremated... its really really burnt---

[00:08:21] Interviewer: Yeah, you sent me a picture of that, didn't you?

[00:08:23] Becky: Yeah. So he'll like examine it. I have to make sure the burnt side is on the side that hasn't got the Nutella, because he inspects it basically, underneth, and if it isn't as burnt he'll put that bit in the - in the bin.

So that's what he normally has. He normally has it a couple of toast with Nutella in the morning. However, for the past week, or so he's like "no I don't want toast mommy" he's wanted sandwiches. So obviously I want something in his stomach before he goes to school, so I've been giving him chocolate spread sandwiches--a couple of those.

He obviously has packed lunch and then again he will have a chocolate bread sandwich and then he'll have three pieces of-- he likes this millionaire shortcake, basically chocolate and caramel, and then like a digestive underneath, they're like bite size. Sometimes he'll eat those at lunch time, sometimes he'll come home with those and he'll just have had the sandwich.

And then, in the evening he'll either have again toast or he'll have sandwiches, it's always in that order. He'll always have that, then a packet of Wotsits, then two packets of those little Kidolicious smoothie melts, and then he'll have four or five of those shortcake biscuits.

Um, yeah, I mean, he does eat---I sent you pictures of some--he does eat sausages, but he won't have anything with them; he won't eat potato, he used to eat pasta, he wont eat pasta anymore. He just won't have anything with it - you know, if I give him sausages, it's basically a plate of sausages, I have to skin them, and he won't eat skinless sausages, I've tried those and he won't eat

those. And then that's-that's all he'll have. So he'll have the sausages, then Wotsits, fruit melts, cake.

Um, And then another thing that he'll eat which I showed you, I sent a picture, which would be the chicken and he'll have that with pesto, and I always - 'cause I do that for Bea, his sister, she'll have pasta or maybe sweetcorn, or whatever, I always put it on his plate but he'll never touch it. He'll just eat the chicken and then Wotsits and fruit melts. Yes, that's basically what he has. And he only drinks water as well.

[00:10:42] Interviewer: Okay. And how do you feel about his eating problems?

[00:10:47] Becky: Um, I-I do get very - I can't get frustrated with it. In terms of - I just feel like he's missing out on so much more. You know - it with - you know, simple things as going out shopping for the day, and I always have to take a packed lunch with us because we can't just pop into a coffee shop or---you know, he won't have a sandwich from there, you know. So uh, it would be nice to give him other things. The problem I have is, I have in the past cooked him other things, but just knowing full well he will not - but he will not try it. he just refuses. Rewards systems don't work with him. He just would rather not eat something and be without the reward. To me, I think he enjoys eating what he likes, but I mean he just does it because he has to, because he feels hungry. I don't think he's like, "Oh dinner time." He just does it because he's hungry, just something he has to do really.

Say like on the weekend we went out, we went on Sunday to like a Christmas market and Scott and I got a slice of pizza and we'd taken the kids packed lunches and and actually Ben did say, "Oh mommy what have you got" and I said "pizza, would you like some" and we always offer him and it's always no and I never push it. He actually, he didn't have any of the topping he had a bit of those little crust. So he, you know - wanted to try something a little bit different, he will just try a bit but made sure there wasn't any tomato on it, or anything like that really.

Um but yeah, and to be honest you know, um, in the questionnaire I said no disruptions at meal time. It's simple because, is that I give him what he wants, so there's no, you know, there's no tantrums, because I've never-- I don't put him in that position, because he's not particularly a big child and also in the past he's suffered from-- um-um, well at first we didn't know what it was, and it seems to um have gone by the wayside now, he hasn't gone in that state in a long time, but they called it Cyclic Vomiting Syndrome. Well, we noticed that he would be ill and sick in the morning, and I always noticed that the night before he had completely not eaten anything, so you know, I do - I don't know if his blood sugar levels was off. But you know, at the moment I just can't risk him not having anything to eat so I just give him what he wants basically.

[00:13:45] Interviewer: And so - how do you think his range or his eating preferences affect him, if at all?

[00:13:54] Becky: I'm sorry could you repeat that sorry?

[00:13:55] Interviewer: How does his eating affect him, if at all? Does he, sort of, is he aware that his eating is different from others or does it bother him?

[00:14:03] Becky: Um, if he is aware, he's not bothered. I mean he doesn't seem--for an example is say, the other weekend he was invited to a birthday party, which is lovely 'cause he's now really much better at participating but my heart does sink when I see the table being set out and they've got to sit down and have something to eat and I know full well that he's just not gonna have anything. And you know, the other weekend when we went to party and I did say to him that - Ben, you know, you've got to sit down as everyone else does to be eating, and I said would you like to try it, I even stood away as the other mums tried to like offer him sandwiches, and he just sat there and didn't have anything. Um, but he doesn't seem bothered by it as long as he doesn't have to have anything, then he's fine, he just sips some water and that -and that was it.

Um, he's not really sort of that curious about it, he's just like I don't want anything and I'm fine to sit here as long as I don't have to have anything really. In fact, he came home with a letter the other day from school and, um, I think

his teacher has explained to the class what the letter was and basically that children who have packed lunches next week they can actually swap for the day, 'cause they are doing a Christmas lunch. He did come home a bit worried, he is a little bit of a worrier, and particularly as he's gotten older he worries over things; He's like "Mummy Miss told me that we can have a school dinner just for one day, but I don't want to I don't want to I don't want to". So you know I had to tell him, you know, "you don't have to, it's a choice, you can still go to school with your packed lunch. you don't have to have it." So yeah, I thought maybe going to school and maybe seeing other children you know like eating other things, but yeah, he's just not bothered, no.

[00:16:07] Interviewer: Do you have any concerns - do you have any concerns about his eating and his health? Do you think he's -

[00:16:12] Becky: Yeah, I mean he's totally-- um, I think he's physically not getting everything that he should get because he doesn't eat any fruit or veg, he has no dairy, like calcium, um, he might have a little bit of butter here and there, but he doesn't have yogurt, he doesn't have cheese, he doesn't drink milk. And so yeah, I mean, you know - it does worry me, obviously his diet isn't balanced really and so me and my hubby have concerns that he doesn't, um yeah - he's not getting what he should be. Um-um in terms of that, he doesn't look unhealthy, he doesn't look like he's lacking in anything but I'm sure he is because, he doesn't have-- you know--I'm-I'm sure he's missing a lot really.

[00:17:05] Interviewer: That reminded me it's - your 5th photo is a packet of Movicol, is that right? How long has he been on that for?

[00:17:13] Becky: So, he's been on that, since, i would say, a year or just over a year. He has on like a sachet a day but now, cause he's eating more in terms of more than what he was when he was a year, so with that I've given him half a sachet every other day. But a few weeks ago now, he had to a bit of a stomach upset, so I didn't give it to him, 'cause you know, he didn't need it. But I left it to see, and he - he definitely - he still needs it cause he's obviously not eating roughage, so he's got a bit of constipation because of his diet.

[00:18:02] Interviewer: How-how does that - how does this constipation affect him? Does it cause problems or it-it well under-control with the Movicol?

[00:18:10] Becky: Um, it's well under-control now with the Movicol, I remember a year before that he would suffer really terribly, you know, he'd be trying to go and he couldn't, yeah it was awful and then he'd be scared to go. And yeah, but we haven't had that in a long time because the Movicol certainly helps it, yeah.

[00:18:30] Interviewer: Okay, that's good. So looking at your other photo - so, you've got the Movicol - and the peeled sausages, how long does that take you to peel the sausages?

[00:18:39] Becky: So this is he thing, yeah, so basically, I work three days and I don't get home until a quarter to six, so by that time they're basically really hungry, so that tends to be when, you know. If I knew he was going to eat other meals I would cook some other meals, because I know he normally has like a sandwich or what-have-you, and also the days--my partner he works overseas so he um - you know, I'm on my own a lot of the time, and so the days I'm off and I've got more time. But yeah, that could take me about an hour to prepare, cooking the sausages and then you know - and then peeling them, takes about an hour really, and you know. And then I give it to him, as soon as I give it to him though he's eat - he's eaten the lot, and I'll say, I give Bea a couple and she'll have like pasta with it or whatever, where as Ben will just have--and there was a point where he could eat six sausages, I mean, I try to peel them as carefully as I can but obviously some of the sausage gets taken away because there's peel in them. The last couple of times he's had six I have to say in the night he has been sick and I just think its been too much for him on his stomach 'cause he doesn't have anything else, so now I only give him four, and I do give a him a bit of bread on the side, just to-to have something with it, whilst he doesn't really want the bread, I just think it has been a lot of sausage meat - it can't be, but yeah, it can take about an hour to do and as soon as I give it to him, he's like, "Mummy I'm finished."

[00:20:24] Interviewer: And you said about his cyclical vomiting, is that something - is that something he had from when he was very young or was it something that's quite recent?

[00:20:32] Becky: Um, so I think it started when he was about, um, so I'm thinking now - say three, I think at the worst, I think I'd had Bea so yeah, Ben must have been just coming on to three. Um, so yeah, there was no sort of rhyme or reason it was just uh--he would wake up in the morning and, um, just be very very lethargic and I always find that he would sleep in a little bit - which is very unusual for him - and even now he's a very early riser--and then he would just lie about and then all of a sudden about after an hour or so after he'd been up he would just start being sick, and he would be sick a good few times until it got to about midday--maybe a bit later and then he would fall asleep. And then after a long sleep he would then wake up and then would say he was hungry so he'd have some toast-- and then like come evening, he'd be running around you'd think I was--you know, if you'd seem him in the morning you'd think he's a completely different child, it was really strange.

Anyway, we were - we were referred to the paediatrician at Lewisham, yeah, we've been to numerous appointments, he's had lots and lots different test, like a CT scan just to rule out all the horrible things. To be honest, actually it's a bit of a conundrum, we don't really know the reason is--and because it happened--the symptoms they're all the same, the length of the episodes is the same, the time of day is the same, so they then--we just had to say--we could only put it down to the Cyclic Vomiting Syndrome. Um, she did say that it might be something that he would grow out of. And I have to say, I mean, it's been a long while since he's had one of those episodes. He's had a couple episodes where he's been unwell, but, he'd been sick once where he had a bit of a temperature but um, yeah, whether it's something--well I hope he's outgrown - you know, it's just um -

[00:22:41] Interviewer: And it's interesting you thought that maybe it might be related to him not eating the night before.

[00:22:45] Becky: Yeah, well I - that would be almost a sign but if he doesn't-- if he wouldn't eat like any dinner and then uh, I would - I'd reckon he's gonna wake up tomorrow and feeling of being unwell and that would be - that would be - a sign, yeah have anything the night before then he would have the sickness, yeah.

[00:23:08] Interviewer: Okay, and so far, um, for Ben, all of his eating problems, do you think it affects the rest of your family? Does it affect his sister at all?

[00:23:14] Becky: Yeah, so basically Bea is three years younger than him and she absolutely idolises him, and um, so whatever he says, she will do the same. So, I have to say - I mean, one, she will eat more things - and she will eat fruit and what-have-you. She always says, "I want what Ben wants. I want what Ben wants." So, her diet isn't by no means the greatest because she-she just wants to copy-copy Ben so yes, it has really affected, it does affect, it does have a knock-on effect on us, you know in terms of, like, say, like people who, you know, I envy people you know i bumped into a family whose boy is in the same year as Ben and they were just going to, you know, a pizza place and you know, I would love to be able to do that and it's just not possible at the moment, you know it's just not we can't really sit down and have a family meal, because he won't eat anything, you know, whereas you know we could sit down and have a family meal, but he would like - he would have a sandwich instead of what we're having. So, um -

[00:24:22] Interviewer: Do you manage to eat out at all or go away?

[00:24:26] Becky: So, I mean we do go away and so, for the last couple of years we've gone on holiday to Tenerife, with my parents.

We always go self catering so there's a kitchen area we could do sandwiches and what-have-you- we do tend to eat out of the evening as well what we would do was, say, by the time we would go to the beach and then to eat, the kids would be hungry anyway so we would have a sandwich, then we would go out and eat out but we would look on the menu and there would be - they would

have - quite a few restaurants have sandwiches and things, so we would, um, order some sort - and he would have them - he would sit and eat so yeah, that was quite good. I mean, the year before - um, yeah, absolutely no - he wouldn't have anything at all. And I'm - and you know, there you are sitting and eating and you are not ordering - 'cause you are just wasting money, you know, there's no point in buy - you know. And so they must've thought, "Oh God! You know, you're not buying anything for your children, that's really mean." But um, you know, obviously they've already eaten, if not we'd happily buy them - but anyway, this year it was a bit better because now he's started to eat sausages and that was always something that - you know, a lot of restaurants - now that way there's a couple of times where they were like, frankfurters, and he wouldn't eat those. But um, so there were a few times that he, you know, he could sit and eat some - oh, you know, they would bring out some sort of, you know, French bread thing they'd start with and he - you know - he does eat French bread. So um, you know, he might have a nibble on that or whatever. But yeah, so - but that-that's the extent of our eating out, really.

[00:26:08] Interviewer: And, have you, have you sought any, um, professional help in the past for his eating?

[00:26:14] Becky: So - um, I think I've actually - we've been to see you.

[00:26:19] Interviewer: Yeah I think you have. Yeah.

[00:26:21] Becky: So I think that you - yeah, we were referred to yourself, uh, I can't remember when it was - quite a while ago now, uh, uh, other than that now actually there's some occupational therapy session.

[00:26:39] Interviewer: Mm-hmm.

[00:26:40] Becky: And the lady, the girl who we'll be seeing - that's actually - that's now been put on to do, um, they do some intervention um, sort of sessions with food - so I think - I think the - I think there were some in January, but we're not going to be on those 'cause they're full up so, I think we're looking at Easter. Um, and - um, yes, so we're down to-to do those. Um, I'll be intrigued to see how-how it goes. I mean, she obviously - she assured me that there's no

force-feeding or anything like that. But no, um - yeah, I mean yeah - so, um - so that-that's something we'll be doing, um next year anyway. Yeah.

[00:27:21] Interviewer: So is it - his eating problems have been going on for quite a while, so when they first started did you get any help, did you go to your health visitor or anyone or was it something that you just tried to sort of muddle through on your own?

[00:27:30] Becky: We did seem to sort of muddle through on our own, really. Um, yeah, um-

[00:27:35] Interviewer: Did you think asking for help or was it something that um-

[00:27:40] Becky: Um, to be honest yeah, I mean yeah and I don't know when realised I was being a bit naive in terms of thinking that it might get better and so yeah, probably wasn't as proactive as what - well, I mean at first, and he says that he could, you know - it wasn't as bad 'cause he was eating a bit more, but then it got to a stage where, you know, it's not good at all, really. Uh -

[00:28:10] Interviewer: And when you - so when you came to see um our dietitian service, was that something that you'd asked for or was it what that the doctor said?

[00:28:18] Becky: No, I think that was from - yeah, so I think it was when we had uh, the - uh, we'd seen the pediatrician. I think it was the time he'd been diagnosed and so she was obviously asking us all about it and we said - you know, and we were concerned about his eating and what-not so, she said "Then, would you like us to do a refer you to see our dietitian, so we-we said yes. Yeah.

[00:28:38] Interviewer: Okay, great.

[00:28:40] Becky: And actually I think, actually before that we-- he was put on the list to see um, a dietitian but I remember that we were taken off the list 'cause I think, yeah, so yeah, and I think that, yeah, I think we would be on top of the list then we would be taken off and then put on back again so, yeah.

[00: 29:01] Interviewer: And what sort of things have you found have helped with this eating - has the school given any help or anything like that?

[00:29:09] Becky: Uh, no the school hasn't, I mean, um, it's quite hard - but, um - and because the way Ben is, and so, you know, because we didn't want him to be so unsettled at school and to try and - we-we haven't really sort of tried to - you know - maybe, tried school dinners or anything like that. And I think when they have them, you know if there's any part - you know they've had parties at school or, you know, I think they all say to Ben, "Would you like to try something." They don't - they don't, you know, his teachers know and they don't push it, really. So um, I mean, they've been - the school's been amazing. They haven't really, sort of, um - like helped with food or eating really, but we haven't asked them to either. So -

[00:29:57] Interviewer: Yeah okay and in an - in an ideal world, what sort of professional help might you have wanted, would you - might have - might it have been useful to have some help earlier on or do you think it was -

[00:30:07] Becky: Yeah, I think well, it would've been, um - I think probably, yeah, we probably should have gotten some help beforehand and just you know just um, maybe, you know, just some tips - or you know just how um, yeah, how you, we, you know any ideas to get him to eat other things, or you know or um, if there any groups around to talk to people who have the similar problem, you know, just 'cause you know you just - everyone just takes it for granted that your children will eat whatever and, um, you know and you just sort of - I think, oh, well we've got a child who doesn't really and has got a really restrictive...

So um, yeah, I just think maybe um we, yeah - we could've probably - it would be probably been good if we had a bit more support at the beginning really.

[00: 31:01] Interviewer: And did you, I mean, did you Google it or anything like that, did you find any sort of, um, any resources that helped you or was it something, I mean, from what you are saying, it's sort of a problem that gradually sort of creeped up on you and -

[00:31: 14] Becky: Yeah, exactly. Yeah, so whilst - you know, it just - yeah, so it just something that didn't all - it all just sort of happened over time, really. And then, yeah, then we're faced with, "Oh God, you know, he's not really eating much at all now, really."

So, yeah. Um, I mean we looked up.. particularly when he was just diagnosed with autism and just um, you know - you know it's just like - a lot of autistic children can um, you know, have restrictive diets or you know, uh are quite um particular of what they eat - etc about texture and things like that. And that-that's it really. Yeah.

[00:31: 55] Interviewer: Okay. And um, so-so now you've had a bit of help so that you've had the OTs involved and things like that, has that been any help or what do you think is the best help you've received so far?

[00:32:05] Becky: Um, so, I don't think we've - well, in terms of his eating, nothing's changed, but I mean, yeah, nothing's really seemed to have worked really - we've just - I've done it - and well, 'cause it hasn't got any better, we haven't um, yeah - so, I can't really - I can't really say that anything has helped us really.

[00:32: 34] Interviewer: Sure, okay, and um, have you ever looked at - it's sort of an unrelated question almost but, have you ever looked at things like special diets or supplements for your child?

[00:32:43] Becky: So, um, we have, so we use, so w-we give Ben some Abidec. Um, but, um, I think after seeing yourself we were given, um, a fibre supplement, um, but we just- W-we can't get it down him. The problem is, is that, um, he will only drink water so, um, I- In an ideal world I would love something, um, like Abidec - a very small amount which you can put in a syringe and you can just push- You know, put it to the back of his mouth a-a- and it's gone. Anything that has that- has a bit of taste or, I think the supplements we were prescribed it had what- It was really, it was quite a lot he had to drink, um and it wasn't tasteless and it had bits in it and he got really, really distressed when we tried to give it to him and it was just, you know—

[00:33:32] Interviewer: Mm-hmm.

[00:33:33] Becky: In the end he just got so upset it was almost making him sick really so you know, I just, yeah, so in terms of, you know, 'cause you feel- You get these, you know, smoothies and- But he just won't, you know, he won't drink a smoothie anyway so, you know, getting something down him is a problem because really what I would need ideally is something that's very, you know, it's a small amount or something I could put in a syringe and I could put it into his mouth and shoot it down his mouth if-if you get what I mean. Because he thinks that, in a drink—

[00:34:05] Interviewer: Sure. How do you manage to give him the Mov—

[00:34:06] Becky: Oh with the Movicol, yeah, so - and now he likes it 'cause uh - so basically that is in water and it does taste of something but he, for some reason—

[00:34:13] Interviewer: He's got used to it.

[00:34:14] Becky: Will drink it. I don't whether he's had it for so long he's used to it, um, well he obviously is but he doesn't seem to-to pick up on it whatsoever.

[00:34:25] Interviewer: Okay. That's really good, isn't it?

[00:34:26] Becky: Um, yeah. So yeah, anything with bits or- Is just, um, yeah, it's a no-go really.

[00:34:38] Interviewer: Sure, okay. A-and when- When he was first diagnosed - lots of parents see things on the internet about things like special diets like gluten free, and milk free, and lots of different things like that. Is that ever anything that you've looked at and considered, or no?

[00:34:52] Becky: No, no we haven't, no.

[00:34:55] Interviewer: No. And is that just that you've seen it and just thought, "Oh, that's not really relevant to us," or it's something that you wouldn't try or—

[00:35:00] Becky: Yeah just- Yeah, haven't really considered it really. So -

[00:35:05] Interviewer: Okay. Um, and is there anything else you want to tell me about his eating problems and how it affects you and anything like that?

[00:35:14] Becky: Um, no that's something- That's the main thing, you know, yeah, it's very limited, um. Yeah I would love him to have at least a bit of, you know, um, fruit and- You know, a bit of fruit and veg really, fresh food really. Um, yeah just in terms of sort of how it affects us, you know, um, yeah it's just quite- It can just be quite frustrating and particularly with Bea as well, how she will just sort of copy him so, yeah. So you know, deal with - with her as well really, so.

[00:35:49] Interviewer: A-and for, like, you know, if we were developing some sort of extra help for parents, would you access things that were online or written resources or would you prefer, sort of, face to face groups or—

[00:36:00] Becky: Um, yeah, I was-Um, yeah, online 'cause that's really- You know, with working and what have you so you can just do it, so online would be good. Um, and if there was any, sort of, like, sessions, um- Obviously with- You know, obviously I-I work but, you know, if I could- You know, if there was, sort of, like, I don't know, like, sort of short meetings or anything like that, you know, then obviously I'd be interested in going to it really and-

[00:36:24] Interviewer: Mm-hmm.

[00:36:25] Becky: And also just meeting other, sort of, parents new to the area or whatever who's going through the same, same thing as what we are really would be, would be useful, yeah.

[00:36:34] Interviewer: Sure. And what about if we had things like short video clips or anything about it, you know, so rather than—

[00:36:40] Becky: Yeah.

[00:36:41] Interviewer: Rather than, you know, if- For people that can't get to groups and sessions then—

[00:36:46] Becky: Groups and- Yeah, exactly, as I say, I mean I would attend but obviously would be in- You know, I'd have to, you know, be d-dependant on

whether my work, working and that so it might be that I'll be out all day - Yeah, videos and things that's easy accessible would be, um, would be useful as well.

[00:37:02] Interviewer: And the other, sort of, idea of something that might help is something like a, sort of, almost like a self-help manual. I know for some, for other, sort of- For the- I mean, for things like, um, you know, anorexia and other eating disorders in older children then some researchers have developed things like, you know, self-help manuals that p-parents can work through with their children and work through different activities.

[00:37:23] Becky: Yeah definitely, any sort of guidance or- Yeah definitely, anything that would, you know, would help or, you know, something that we could- We could try, definitely.

[00:37:32] Interviewer: Okay. Um, okay, that's great. So, um, thank you very much for your time, um-

[00:37:39] Becky: Oh, no problem.

[00:37:40] Interviewer: So is there anything else I can a- Anything else you wanna ask me or anything like that?

[00:37:44] Becky: No, I don't think so.

[00:37:45] Interviewer: No, so it's been—

[00:37:45] Becky: Told you everything.

[00:37:48] Interviewer: It's been great—

[00:37:48] Becky: That I can think about Ben and his eating.

[00:37:52] Interviewer: I know, I know. It's been great to talk to you, um, I think your responses have been really useful for um, for us.

Appendix 19: Participant 3 transcript

[00:10:07] Interviewer: Fantastic, okay so first of all thank you so much for agreeing to the interview um particularly as it sounds like you've been um particularly busy.

[00:10:13] Interviewee: Yes, yes, I have. [laughing] That's cool, that's life, that's life.

[00:10:20] Interviewer: Thank goodness, I really appreciate it. Um, so first of all, um, do you want to tell me a bit about who is in your household. You said you've got two-two children on the spectrum.

[00:10:29] Interviewee: Um, i-- there is myself and my husband, we only actually got married this year-

[00:10:32] Interviewer: Oh Congratulations.

[00:10:33] Interviewee: -Um, we have been together for quite sometime. Um, and our eldest son was nine on Saturday and our youngest son was seven on Saturday.

[00:10:40] Interviewer: Okay.

[00:10:41] Interviewee: And, so-- uh we are quite a solid unit, um, it's just us four- we don't have that much external help. Um, you know my mum died when I was younger. My sister helps out now and again and she does live local. But my husband's parents and most of his family live around the country like up north. So we have a couple of good friends that kind of help but essentially we do everything on our own. We are our own team, Team Carter.

[00:11:11] Interviewer: Fabulous, um and tell me a bit about your children.

[00:11:17] Interviewee: Christopher, um, my eldest son he is a real character. He, um, has always been very, very full on. I used to call him the Tasmanian devil. When he was about two, he just turned into this little devil thing, even though he was absolutely beautiful, um, but he was a hundred miles an hour. Um, he was up the walls, he was around the corners before you'd even opened your eyes. Um, and he has calmed down a little bit, he is a little bit more, I'd say

he has found technology, um, and he has calmed down slightly because he now stims himself via technology as opposed to in a physical manner. No he does do both, but his general movement manner around the house isn't so manic.

Um, and my younger son is ticking on.. Christopher has verbal dyspraxia.. Even though he-- we can now have a conversation he didn't-didn't really talk until the last couple of years. Well he's been talking all the time but we just haven't been able to understand him. Um, I mean, for instance, he was three and a half before he called me Mum. Um, and since I knew very early on that he really probably wouldn't cope, well I wasn't prepared to let him go to a mainstream school because he couldn't talk. Um, even though we got a statement that gave him some hours it wasn't enough, because I just thought how would he communicate, he cannot even tell the teacher if someone's been unkind to him or anything like that, he can't ask for a drink, because at that age he really couldn't express himself other than more than a few words.

Um-- and so I consequently went to a special school-- you know once i got the statement, I went for a special school and it was the best thing I have ever done, because he has come on absolutely fabulous and he really wouldn't be where he is now, at nine, if I had gone for sort of mainstream school. Um so with his dyspraxia, his verbal ... and obviously he has other kinds of learning needs, not quite sure how to describe them, no one's ever described them to me, um but yes he's doing very well, um, considering his struggles and his challenges. Quite an angry boy, quite an aggressive boy in that respect.

Um, my younger son, completely different kettle of fish, much more calm-- he is not-- he is much more less aggressive. Pretty much non-verbal, the words that you do hear out of him you have to pull out of him, as I have to say you have to make him say them. You have to say mum, say Mummy, drink and then he goes "Mum." You can only say one word at a time, and he will say Mummy, and I would say "drink," and he would say "dink" The word that you don't pronounce-- I've only just been told that Christopher is described as verbal dyspraxic. I wish I'd known a few years ago because whenever anyone talked to him, I can't

understand him, what's wrong. I had to say, hmm, “He just cannot pronounce his words properly.”

He has never been formally diagnosed which I believe comes from a Nuffield Centre center? But Christopher has never had cause to go there whereas Carl, with his non verbal I’m not quite sure if there is a verbal dyspraxia that-- would then describe him as dyspraxic, or do you have to have language to be dyspraxic, does that make sense?

[00:14:31] Interviewer: Yes, I don’t know. I’m not sure.

[00:14:32] Interviewee: Well with Carl does really have, I would call him more non-verbal, you know what i'm saying? So we have much more big communication struggles and challenges with Carl and he stims a lot, he needs a lot of... I would call him hypo-sensitive as opposed to hyper. Um, he slams himself, he runs up the walls, he jumps the wall of the bathroom, he would find a corridor and he would run from one end to the other. He would skate on his knees and he needs lots of pressure and lots of kind of sensory, um, stimulation and he creates it for himself mostly - sitting there, spinning his toys and then surrounding himself with them and just-- spinning around, in a circle.

[00:15:20} Um, but that's calmed him down a little bit but he is very much insular, very much happy into his own world, really doesn't care for other people, when I say that, i mean he loves us, he knows who we are, but he doesn’t care for friends at school absolutely 100% happy in his own world doing his own sensory stimming things and as long as he is happy like that, you know I’m happy.

Carl has a lot of sleep issues, so he is much harder to get to sleep and keep asleep so we have a lot of up-and-down nights.

Christopher we have some issues in that respect but we have more toilet issues that we have. They wake up for different reasons.

So that's the kind of background but I suppose you are more interested in the food [laughs].

[00:16:14] Interviewer: Yes, tell me about what their eating is like, what they are eating.

[00:16:19] Interviewee: Um when they were babies, it was okay. Um and I am very, very grateful that I was able to get, um weaned them on a lot of home foods. And I was the home cook. I would do a stew, I would do, all the potatoes and vegetables and that sort of stuff. you know, I would boil it all by myself. They were weaned properly and they ate everything and it was great, and they both got to a certain age and their taste buds completely changed. And then that was when the problems started, they stopped eating any kind of wet foods.

Are you going to do the study on both boys, are we classing them both as one or would it be easier to stick to one, what do you want?

[00:17:03] Interviewer: Well it's probably-- if we talk about one and then we talk about the other and then we talk about overall how it affects your family.

[00:17:12] Interviewee: Yes, no problem. I think i'll start-- it's always easy to start with the oldest. So Christopher, yes, he would eat things like salmon, tuna and avocado and all the easy stuff that all the babies-- and then he just-- hit two, and went of everything, m even before actually. Actually sometimes I cannot remember their early years because they were hard, because we had a newborn baby and this sort of amazingly energetic toddler. Though i kind of-- I don't really remember too much, but I always done a lot of carrots, pepper, cucumber. So, even though he wouldn't eat perhaps a ham sandwich. I would fill his plate with-- you know a bread, a piece of cheese and lots of fruit and veg.

So now consequently both their diets are really restricted but I am happy they get enough food and veg into them, it's the proteins and calcium that I do struggle with, because I do look at it in terms of food groups and what they are getting as they are growing. Um, so for instance then, Christopher developed IBS. He stopped drinking milk and yogurts at about three. Um, I have struggled since then to make sure he has calcium intake.

Um, but we kind of settled on-- i mean they've always ate McDonald's. you know when you shoot yourself in the foot for ever taking them in there? And you

know and also the fact that its always the same, you end up going back there. Because with autistic children you know wherever you go you can get the same burger. Because you know I have literally driven miles out of my way just so I wouldn't drive past one because I was determined that we're not going to have one. Um but you know essentially they would eat chips from McDonald's but if I ever done like chips myself, not as in like deep fried or anything like that but chips like in the oven or even if i bought oven chips they would never eat them.

But Christopher would sort of like settle on, I just learnt very quickly not to give him any wet foods. He wouldn't eat any more stews or any kind of casseroles or um mild curries I would do, anything that had meat and vegetables in it basically that I could get down them um he would basically eat.

If I run through his diet, which has been, pretty much the same for about the last five years now... In the morning he would have dry cereal, an apple and a glass of water. Um, I cut the apple up**.** I made a fatal mistake there as well. Then for lunch he wil have a cheese sandwich, white bread only, butter, and he will have some chopped up carrot and cucumber, a small apple, which he will nibble, and a pack of crisps as his packed lunch. That's standard, absolutely the same everyday and as a-

-evening it alternates between-- becasue he's got IBS I try to keep to semi-gluten-free so I'll go with gluten free pasta, gluten free sausages, he will only eat-- a special pasta with an extra special pattern, um, and he would have, a portion of pasta, dry pasta, plain, or a portion of plain rice with some whatever vegetable i gave him at lunch, I would try and mix it for evening then, because Christopher will only eat pepper, cucumber or carrot and an apple, um, he doesn't eat any other fruit and he won't.. oh he just recently started eating lettuce, just a bit of lettuce just cut up, just washed lettuce no dressing no nothing. Um, so i would then give him either chicken dippers or a fish finger or the chipolatas he likes-

[00:21:00] Interviewer: Mhm.

[00:21:01] Interviewee: -with either the rice or pasta and a bit of veg-- so i-- a bit of pepper if he had the carrot and cucumbers for lunch, but then I had to stop giving him pepper because it was flaring up his IBS so we were down to only 2 vegetables. But that's kinda been the same for about four, five years now, Zoe, to be honest and, um, sometimes I've tried to change his bread or put some seeds in it but that flares up with his IBS so, am a bit more governed with him, um, so you know this massive thing he tried a new vegetable recently-

[00:21:00] Interviewer: Mhm.

[00:21:01] Interviewee: -he's started to eat a little bit of lettuce, um, but and-- its hard trying to get him to eat a different type of bread has made his tummy bad so you sort of like take one step forward...

[00:21:41] Interviewer: Mhm, and how do you get him to try, um, new things?

[00:21:44] Interviewee: Oh, really hard. It was just, "please take a try". It could, because I can rationalise with Christopher a bit more. This is only really been in the last year-

[00:21:51] Interviewer: Mhm.

[00:21:52] Interviewee: -he's been absolutely willing to even try, and put it in his mouth before that he would downright refuse, scream, shout, get upset so you just didn't push it. Um, I did used to try the-the effect of, let's just put a little piece on his plate so he gets used to it, try and do that each day or try and put a bowl of something on the table - them kind a tricks over the years. but they just wouldn't get touched and if you tried to offer them they wouldn't, they wouldn't take them, either of them, you know they'd just become a bit upset. But now because we could rationalise with him a bit better and we could say, "well look, you are a big boy now, um, you don't know that it's not gonna be okay. You don't know until you try." and, but, he has made his mind up before he puts a thing in his mouth but the fact is he is putting it in his mouth.

[00:22:37] Interviewer: Mhm.

[00:22:38] Interviewee: He'll still go, "No, I don't like it," But we would just go like, "okay, that's great-

[00:22:42] Interviewer: Okay

[00:22:42] Interviewee: -well done for trying" and leave it. [laughs] Then it would be a little while before we try something else. But to us that's big, he's even attempting to put it in his mouth, and I remember being a kid and trying something and knowing that i'm already gonna say no, before I tried it. You know?

[00:22:56] Interviewer: Yeah, yeah.

[00:22:57] Interviewee: So-

[00:22:59] Interviewer: Does he--

[00:23:00] Interviewee: -this is a play going on in there as well but yeah--

[00:23:02] Interviewer: Does he enjoy eating? Does he enjoy meal times?

[00:23:06] Interviewee: I don't, personally, I find, um, no they can be okay. No that's, that's wrong for me to say. They're not unpleasant, they're a lot better, than when they were kids-- when they were little it was awful because you just never know, because they could communicate anything, things often got thrown, that kind of stuff but they are really quite pleasant now but I find it quite monotonous because now it's just the same thing day in day out--

[00:23:27] Interviewer: Mhm.

[00:23:30] Interviewee: And I do find it's, [sighs], you know I find it find it, i still have problems with knives and forks, and trying to keep them sat down, because they need to move it's not rigid, they don't have to completely sit on that chair, without moving or anything like that so we will allow some some sort of kind of movement or stimming if i think they're a bit kind of combusting, but I try and keep it like "now look, you gotta come back soon. We're sitting at the table," That kind of thing. But they are not, really stressful, but they are a little bit tense.

[00:24:01] Interviewer: [laughs] and how do you feel about his range of foods? Do you feel--?

[00:24:04] Interviewee: Oh, no I would love them both to eat some more, but because I feel [coughs], so what I do, I felt-- because Christopher, would at one point, um, within his diet, I would, feel like, if there's a bit of protein, a bit of calcium, a bit of vitamins you know which covers him, sort of, from the veg. Um, and calcium-wise I found him some calcium sweets that he's only just now started to take. Um, how did i cope with that before, I don't remember actually, but for instance I bought some calcium liquid and he wouldn't touch that for ages but like I said last year it's been a game changer with Christopher because he is now open to actually trying and-and I think - that was it - I explained to him that he needs to take this because his bones needs to grow and because he was young and you know cos he doesn't drink milk and it upsets his tummy we need to find another way to help make sure his bones are strong and, you know, he is growing right and stuff like that and, you know, I kind of-- weedled it in that way a little bit, um, but sorry, what was that question again?

[00:25:06] Interviewer: I was saying whether, whether he and oh no. I was asking how you felt about the range of foods he eats.

[00:25:10] Interviewee: Thank you. Am not overly happy, I would like it to be a lot more varied but I feel like I have got most food groups covered.

[00:25:18] Interviewer: Yeah.

[00:25:19] Interviewee: I put that down to, like I said when they were young weaning them on veg sticks, carrot and cucumber, things like that. Okay, each child eats different fruit and veg, but at least they eat them, you know what I mean?

[00:25:30] Interviewer: Yeah**,** You said that you still have problems with things like cutlery and stuff?

[00:25:34] Interviewee: Yeah, they both tend to wanna eat with their fingers.

[00:25:38] Interviewer: Okay.

[00:25:39] Interviewee: Um. Knife action, they just don't get it, I think it also comes down to, unless you're sitting-- i'm not sitting with them-- but if you're eating alongside them, you're constantly putting your knife and fork down to hand-over-hand their knife or fork. You see where i'm going. It's a constant to-and-fro, you know what I mean? They use their forks okay and their spoons okay but actually knife action and or even if they just wanted to put some-- put pasta onto a spoon for instance, you know, as opposed to forking it. There just needs to be a lot of support and I kind of blame myself for that maybe I wasn't so strict with it, when they were younger or perhaps I should have tried harder, um, but life was hard enough it was one of the things that probably feel through the net, d'you know what I mean?

[00:26:28] Interviewer: Sure, did you get any help for it when-- have you--

[00:26:31] Interviewee: No not really, I-i do see someone at the hospital because of Christopher's IBS.

[00:26:38] Interviewer: Uh-huh.

[00:26:39] Interviewee: I did approach someone when Carl was - that started with his food problems and then because they referred me to dietitian from Kaleidoscope and then you know his other problems popped up so I didn't see someone for then [sic] him but my younger son, I did speak to somebody at the Kaleidoscope about his food when he was probably about three or four I got referred to a dietitian and I had one appointment and because he didn't really have any problems, they discharged him from the service. I never got back to take, I never got to take Carl back-

[00:27:12] Interviewer: Mhm.

[00:27:13] Interviewee: for any follow up any kind of work to do with his eating because I could, it didn't, have any, have enough problems and because their service was so stretched-

[00:27:21] Interviewer: Mhm.

[00:27:22] Interviewee: -it was-- he got cut because he was one of the least-- problem-problematic.

[00:27:26] Interviewer: Mhm.

[00:27:27] Interviewee: And at the time I just read the letter and then went hmph, okay. I was a bit disappointed but because.., but then equally, you know when when you've got two kids with special needs, life is destined to be sometimes a long round of appointments-

[00:27:40] Interviewer: Mhm.

[00:27:41] Interviewee: I'm constantly at Kaleidoscope or constantly at the school for a review, and when Carl is under the hospital zone so you don't, I wouldn't, I wasn't going fabricate something up just to keep him on the list, you know what I mean?

[00:27:53] Interviewer: Yeah, Yeah.

[00:27:55] Interviewee: Um, and because he was eating and when I looked at it on paper, you know, you know he-he's eating his fruit... he's eating some fruit. He eats more fruit than veg does Christopher, because I thinks he likes the sugar more, um, it's a bit more sugary. Um, when I looked at it, I thought yeah he can eat that and he can eat that, and I just decided to run with it, you know? I thought, "well what are they going to say? They'll say he does eat this and he does eat that.." and you know as long he's drinking milk - which he was at the time -,[coughs], you know the kind of you know, get on with it kind of attitude, um, I just got on with it.

[00:28:29] Interviewer: And with, am with Christopher he said that, um, you know his eating sort of went downhill at the age of two or changed from him being a better eater.

[00:28:36] Interviewee: Yeah, a quite dramatic change then.

[00:28:38] Interviewer: So that age did you seek help? Were there any sort of health visitor--?

[00:28:42] Interviewee: I just took it as normal toddler action. But because at that time i was starting to become aware that there was something else at play, as well. So he's really quiet now. I was more intent on following... what it was at-- I'd fallen pregnant. So i was already--

brief history, i remember-- at about 10 months, looking at Carl, and thinking, "I don't know, he doesn't really sm-laugh at me like a baby at 10 months should", and i remember just jumping through hoops one day. And i remember saying it to my mother in law, and i said to her, "He doesn't smile at me like babies sometimes do" and she's like, "You can't say that", and i'm like-

[00:29:20] Interviewer: Mhm.`

[00:29:21] Interviewee: -"No-- but I-- can't explain it", I just had this feeling. And then anyway i forgot all about that. Then about aged 14 to 16 months my sister said to me, "He should be saying something to you by now" like botbot or milk or mum or-- but instead it was some sort of gurgly-burbly-- it really was quite Russian.

By this time I was pregnant so was just waiting patiently and I wasn't aware of it. So for whereabouts of the last six months from June until when Carl was born I was constantly trying to get Christopher to say something so that was my focus. I was trying-- I'm struggling with him doing that you know "you want your bottle - say milk" you know you know because I was trying to test him I suppose. And then everyone said oh he'll talk when that baby comes because he'll be trying for your attention and all that and everyone just kept on poo-pooing it off so food wasn't really the focus at the time, if you know what i mean.

[00:30:07] Interviewer: Mhm.

[00:30:08] Interviewee: It was just a normal-

-you know, uh, for me he was eating-

[00:30:11] Interviewer: Yeah.

[00:30:12] Interviewee: -um, you know, he was fine. It was one of the least of my problems, sort of thing--

[00:30:14] Interviewer: Yeah.

[00:30:15] Interviewee: Um, and then obviously, then I had to, uh, once, and then-- literally, just before I had Carl, um, I bumped into a speech and language therapist at, uh, one of my little kind of toddler groups-

[00:30:26] Interviewer: Mm-hmm.

[00:30:27] Interviewee: -and I jumped on her and I just said, "Look, you know, he's coming up two and he's not saying a word, it's just gobbledy-gook," and then that was when I started down the path to find out, and then I had to wait nine months, at that point, for just my first appointment, to actually get Christopher seen-

[00:30:40] Interviewer: Wow.

[00:30:41] Interviewee: -at, at Kaleidoscope, and by then I was pretty sure something wasn't right. Um, and then it took another couple of months before they actually diagnosed him, so around three was his diagnosis, so he was quite a-- and then I had the baby which just had me up all night, anyway [laughter] because Carl's never slept properly--

[00:30:57] Interviewer: Oh.

[00:30:58] Interviewee: So, um, yeah, it was a really hard year, do you know what I mean? Um, and I, so that's why I probably don't remember too much of the food details of that time, he was-- 'cause again, toddlers at that age, they are very funny-

[00:31:09] Interviewer: Yeah.

[00:31:10] Interviewee: -with food aren't they? You kind of expect that. Um, they kind of-- they're either really good, I get really-- not envious [laughter], I think is the word when they go, "Oh, they'll eat anything [laughter]," and I'm going like-- Oh, and then you look at the child and they're literally wolfing anything down, something like, you know, really hot, spicy food to like Mediterranean olives, and you know [laughter], really wide, varied foods, and I just think, oh my god, and then they're moaning 'cause they're eating them out

of house and home [laughter], and I'm like, I'm moaning because mine won't eat anything [laughter]. You just can't get it right sometimes, but yeah. At that age, it wasn't my main concern.

[00:31:46] Interviewer: Okay. So how about Carl then? So what's Carl's eating like?

[00:31:49] Interviewee: Carl, again, he, um, he was a bit more pickier, starting with his weaning food. He ate, you know, he was good at, you know, the weaning was okay, he ate all sort of freshy, but he was a bit more picky than Christopher was, um, but he now basically has been the same for quite a few years as well.

He did go through a phase where he, after weaning him and then onto sort of complete home food, he went through a stage where he would eat spaghetti bolognese, chilli con carne, but kind of, um, you know just Mum's chicken casserole, a bit of casserole, that kind of stuff, you know? I love a one-pot-wonder, by the way, um, it's just easy isn't it [laughter]? And, um, a, he would, would eat things like that. I could do a, a meal, and know that three of, me and Steve would eat it and he would have a small bowl of it, and things like that. And that went on until he was about three-- three-ish, 'cause it's probably been the last four years that he's not touched kind of wet food then anymore, um, but I had a bit longer out of him, if that makes sense. And then again all of a sudden he's, I don't know what changed, I mean 'cause I changed my recipes, I wouldn't put so much chilli powder in, things like that, do you know what I mean? I would, I would keep things quite mild, but, um, he had the different varied tastes, and then completely stopped then. Why? I have no idea, um,

and even now some of the stuff that he eats, he can stop it, I think he might just get a taste, or it might chew differently and then he'll all of a sudden go, "Bleurgh," and it'll come out, and then that's it, over, that meal finished. Um--

[00:33:20] Interviewer: Does he spit it out? Or is he actually sick?

[00:33:22] Interviewee: He actually will spit it out, he'll either spit it into your hand--

[00:33:24] Interviewer: Uh-huh.

[00:33:25] Interviewee: Um, it's been known to go back on the plate, um, it's been known to go on the floor. Yeah, pretty much anywhere. Generally we try to go, okay, hold on, let's get you a tissue, um, you know, a serviette next to him, sort of thing, um, but yeah. Then that meal is finished, basically, um, so but what's happened, it, what-- from the time-- he will have eaten four or five mouthfuls, or half the meal, already, and then all of a sudden, he's just gone off it--

[00:33:47] Interviewer: Mm-hmm.

[00:33:48] Interviewee: I don't know if it's some, maybe there's a texture he's got that he didn't like, uh, do you know what I mean? We have no idea. Um, but he's, food wise, he-- he used to drink milk for a lot longer, but he now will only drink milk if it's got a milkshake in it, um, you know, like a *Nesquik*, which I'll make up quite-- weakly, because it's got quite a lot of sugar in it. I'm very aware of keeping them out, you know, not too much sugar. They don't really eat sweets--

[00:34:12] Interviewer: Mm-hmm.

[00:34:13] Interviewee: Um, they have, their treat, generally after dinner is a piece of chocolate, which would either be a *Wispa*, a *Kit Kat* or a *Flake*, very, very particular about the sweets that they-- they don't really eat candy other than a *Haribo* bag, you know the little bags?

[00:34:26] Interviewer: Mm-hmm.

[00:24:27] Interviewee: *Haribo*, I think most kids like them. But they wouldn't go into a shop and attack the candy area, do you know what I mean? Because I never, A) I never used to take them in there because I couldn't control the both of them, and um, um, they just never really ate them, I don't really have that, you know, don't, don't really heavily on sweets-

[00:34:44] Interviewer: Mm-hmm.

[00:34:45] Interviewee: -in, in our diet sort of thing. Chocolate we love [laughter] especially me, but, um, so Carl then went on to, he would, uh, he eats dry cereal again. He, he's, the diet's been pretty much the same for about the last four years. He would have dry cereal, but I would be able to get a glass of milk, or a small milkshake-- um, down him, in the morning. Um, he will eat an apple and an orange, a small, he's very, very fussy. It has to be a satsuma, doesn't like any of these easy peelers, um, and then his lunch, he doesn't eat bread, doesn't like bread in a sandwich, doesn't like any butter.

Um, so he's really hard to do lunch for so I make his lunch up and again it's the same every day, and has been for a long time. It will either be a rice cake, couple of rice cakes or a couple of dry crackers, then it will be a tube yogurt, a little box of raisins, a small apple, small orange and a bunch of grapes. Oh and a packet of crisps [laughter]. Which he's quite fussy about, it's either *Skips* or prawn cocktail *Walker's*. Um, he won't eat any others. Um, so, and then his lunch, it really, it's pot luck as to-- it sounds a lot, but the reason there's more in there is because I never know what he's going to eat, so anything could come back on any day.

[00:36:02] Interviewer: Mm-hmm.

[00:36:02] Interviewee: At the moment, it's yogurt. You know, then last week it was the raisins and maybe not the apple, and that kind of thing. So out of that selection of food, he will eat only-- he'll leave two or three then perhaps. Do you know what I mean? Or one or two.

[00:36:16] Interviewer: Mm-hmm, mm-hmm.

[00:36:17] Interviewee: Um, and then dinner is the same. Um, he won't eat fish fingers, it's chicken dippers, sausages. Um, he's just recently gone off of the gluten-free ones, um, because he does eat them, 'cause, 'cause I have to do sets of-- he won't eat the gluten-free pasta, so when I do a pasta meal I have to do two bowls of pasta, two saucepans of different pasta, 'cause Carl knows gluten-free pasta--

[00:36:39] Interviewer: Mm-hmm.

[00:36:40] I don't know how but he does, um, so I-- he would then have pasta, but he will only eat peas and sweetcorn, and a lettuce, and what's the other thing? Now and again he might eat a baby corn or a sugar snap or something like that, but again, he phases in and out of them. So he's been pretty much the same, it would be a plain rice or pasta, one of those two kind of other things, and a bit of veg basically. So and that's been the same for a very long time.

And he will, he-- we are not at the stage where we can get any new down him. He will-- flatly refuses any, he won't even try new, which as I say, well it's only been the last, uh, year with Christopher where we've actually been able to actually get it past his lips. Carl will literally go, "Bleurgh," that's the noise he makes,"Bleurgh," [laughter]. Um, and yeah, no, there's no rationalisation there at all, or there's no bribing, there's less understanding there.

[00:37:36] Interviewer: Okay. And how do you feel about Carl's eating, and his range of foods?

[00:37:40] Intwrviewee: Um, less happy, so with Carl-- with Christopher I feel like, I feel I'm more covered in his food groups. Um, and even though its boring to me, it's not boring to him, it's boring to me, but, um, I understand that's a, that's, that's how he likes it, and that's how, that's how Mummy shall do it. But Carl, I worry he doesn't get as much protein and, um, I say I'm happy on the calcium score [laughter], because he didn't-- I can get a yogurt and, uh, a milk drink down his neck, but whereas Christopher I can't. Um, I do, I don't feel so happy about his, I feel sometimes, you know, what, just a few rice cakes? I don't know what I want, do I want him to eat a sandwich? I think we're just conditioned to have a sandwich for lunch, you know what I mean?

[00:38:22] Interviewer: Yeah.

[00:38:23] Interviewee: And, um, I feel like I can get-- he will eat *Nutella* on toast--

[00:38:27] Interviewer: Uh-huh.

[00:38:28] Interviewee: --at home, but I obviously can't give that to him for lunch. He won't eat a *Nutella* sandwich, but he will eat *Nutella* on a slice of

toast, no butter. So I can do that sometimes for a breakfast at home, or a lunch, um, but generally their food is the same, day in and day out, and I would dearly love them to eat much, you know, I'm not even asking for their, for them to eat what we eat, but just if I was to know what they wanted, I would produce it. Um, but yeah--

[00:38:57] Interviewer: And do you feel like it affects his, his health at all, or--?

[00:39:00] Interviewee: No, they're both quite, quite hardy to be fair [laughter]. Christopher has his own, off his IBS issues, and, um, toilet, um, issues, but they get the odd cough and cold, but that's just being at school like most kids, and now and again they may get, uh, a slight tummy upset if there's been something going around at school, which tends to happen after they go back after the six week holidays, 'cause that's like where they all mix again.

But no, both of them are generally quite healthy. I mean that they look all right, you know, Christopher-- Carl's quite skinny but that's just his build. He's as fit as a fiddle, he's um, he's a runner, he's a trampoliner, so Carl's very fit and healthy in that respect, and, um, Christopher, like I say, he's a little bit of a relaxed, um, sitting down kind of boy [laughter], um, I do make him do activities, we do athletics and things like that, just over the week, but he would much rather sit down with his iPad, whereas Carl would much rather run. Um, so that I feel that their health overall is okay and I don't take them to the doctors for anything than, you know, if they've got a, you know, a graze that I can't get rid of, and it's got infected-- you know what I mean?

[00:40:07] Interviewer: Mm-hmm.

[00:40:08] Interviewee: I don't, you know- -they don't, yeah--

[00:40:10] Interviewer: And you said--

[00:40:11] Interviewee: But i think because i'm aware of-- and i try to-- you know, i'm not gonna sit here and read the food groups-- because i am aware, you know, that-- i feel like as long as i've got them covered--

[00:40:19] Interviewer: Yeah, yeah, absolutely. And-and with Carl you've said that you've seen a dietitian-- with Carl. Have you had any other professional help?

[00:40:28] Interviewee: Um, no, not in terms of food i did see a pees and poos clinic. In the early days, because i mean Carl was in nappies until-- reception, really, he was you know five, five and a half before i could get him out of nappies. So i did have-- a brief bit of help with um the pees and poos clinic**.** Likewise I did actually see the incontinence clinic for Christopher but then that turned into something else as we know he's got a bladder issue and IBS problems so-- and that kind of all resolved at the same time. But now, um, the question is Carl-- was that again Carl--

[00:41:01] Interviewer: Whether you'd had any other professional help.

[00:41:04] Interviewee: No, not at all, I've just now i've done Carl all on my own, if you know what I mean. Once the dietitian discharged from-- their service, because he was the least prob-- you know, there's no reason to see him, in their eyes.

[00:41:17] Interviewer: Mhm.

[00:41:16] Interviewee: I haven't seen anybody about him, I've just done everything indoors, just pulled my head out now and again to my husband. You know, if my sister has him, you know, Carl won't eat round my sister's house.

[00:41:28] Interviewer: Oh okay.

[00:41:29] Interviewee: Sometimes she does take, when I was in hospital for instance. She would have-- sometimes she had to take them from school to feed, you know, to feed them there, you know he wouldn't just eat dinner. Even took my food-- round to her house [laughter] and she cooked it and he still won't eat it.

[00:41:46] Interviewer: Oh, okay.

[00:41:48] Interviewee: You know , that's just him. He's very very particular an that's just **[unintelligible 00:41:52]** .

[00:41:53] Interviewer: What happens at school? Does he--

[00:41:56] Interviewee: I tried school dinners, I tried them because they would have been free and they would be entitled to it, in fact Christopher is probably still entitled to six or seven, aren't they? Um, so-- we've tried it, um we went through--certainly for both of them, um they've had packed lunches for the last few years because in their first reception and year one, we tried a few times when i would, um, i wouldn't send them in with any lunch but they would just not eat so they would come home hungry or the school would let them have extra snacks and things like that. Then i used to, with Carl-- Christopher just flat out, flatly, refused to eat, so he got packed lounge, but with Carl what i would do is i would sneak his lunch bag in so he didn't know he had it, so that they can try him on school dinners. Because it's a three weeks rolling different so lots of differnt things to try And he wouldn't eat any of it, so she would end up pulling the lunch bag out, just to give him something. And then give him extra snacks something during snack time. So no-no school diners. And snacks, i believe is just something along the lines of carrot, raisins and dry crackers. The stuff that Carl does eat so-- i think he partakes in, um, snack time, from my understanding, i haven't really heard much this year, but last year he did. But if they do cooking or anything like that he will partake, but he won't eat it. If he makes it-- if he makes fairy cakes, for instance, and they come home he won't touch it - even though he's made it.

[00:43:23] Interviewer: Does the school do much around sort of food and eating and--

[00:43:27] Interviewee: Yeah, i think, yeah, they, um, i think because it's a special school they do-- if there's a issue they go into it well.

[00:43:33] Interviewer: Mhm.

[00:43:35] Interviewee: Do you know what i mean? Whereas in mainstream schools they won't touch on it, would they? And then children are meant to kind of carry on, so-- there is quite a lot, I mean last term Carl and Christopher did a lot of cooking foods from around the world and--

[00:43:47] Interviewer: Mhm.

[00:43:49] Interviewee: And in Carl's class last year they got everyone to bring in their traditional food and things like that, do you know what i mean? So-- there was definitely work, there was definitely food tech and there is definitely work in the classroom around food-- i wouldn't say it was every week and all the time, but, it's definitely there and, um--

[00:44:04] Interviewer: Which school did they go to?

[00:44:06] Interviewee: Brent Knoll

[00:44:07] Interviewer: Brent Knoll, Okay ya.

[00:44:08] Interviewee: So there's a lot of-- you know their primary is excellent and the early years service is absolutely brilliant. My experience at the moment is mainly early years now Carl's nearly nine--

[00:44:21] Interviewer: Mhm.

[00:44:23] Interviewee: But the whole primary setup is generally very well done and like say there was an issue, they would work, you know with Carl, you know, she tried not to-- the reason i have this Velcro thing with Carl is because the teacher he had last year where she did do food work with him and because of-- she was working quite a lot with PECS with him, last year, just trying to you know, just kind of trying to get him to and ask for something as opposed to just take or [animal sounds] and say thank you, i don't want that, but if it's a food he doesn't want just to say no thank you, or no no, opposed to [animal sounds] making all of these noises. She did do some work like that and then-- you know, then i explained to her how hard it was at home to know what he wanted and then i just took a load of pictures of his- we then discovered last year during the PECS program that he responded better to pictures opposed to symbols.

[00:45:16] Interviewer: Mhm.

[00:45:17] Interviewee: And when i showed him a picture of chocolate as opposed to the symbol one it was a much easier process-

[00:45:20] Interviewer: Mhm.

[00:45:21] Interviewee: -So, I sent her a load of pictures-- e-mailed them and then she printed them up and laminated them for me, so i've got this little book that I can-- I mean to be honest there's a lot more on there, because, um, a few more pictures but equally a few pictures missing like sausage which i never got in the end. But you know it gives me an idea more about the cereals, but he will he will alternate between cereals sometimes cornflakes to cheerios. So he can tell me which he wants.

[00:45:50] Interviewer: Yeah, yeah.

[00:45:52] Interviewee: So, um, that's quite helpful, so yes school do help and I think if you to them with a specific problem, you know, they will help you be trying to write Social Stories and you know doing particular work with that child and, you know, I offer you support to talk about. Or to do things that they offer you to learn things to do at home.

[00:46:11] Interviewer: Excellent. Do you get-do you get to eat out at all with them?

[00:46:16] Interviewee: Oooh, that's a sore subject! Um, Not really. We have very recently.. McDonalds was the only place they'd go.. and in the last two years we've managed twice to go to a Harvester. and Carl through all of his quirks, really likes sitting down and drinking a cup of tea or something like that like sitting at a table. Christopher we can never get to sit at a table whereas Carl... Actually i think what happened was a couple of times Nanny took him into
Bromley and they went and had coffee and cake, and I think that was a turning point for him because Mummy had never done that before because Mummy couldn't do that before with two of them and I think that kind of widened his outside, eating out, you know, experience then. And it was probably only a little muffin or something like that - i can't remember.

But, um, on a couple of birthdays we've managed to go to Harvester and that we've just picked food that we knew they would eat like sausages. Um, peas,

completely changed the menu you know "we don't want what's on there can we have this, this and this please", and-and the promise of an ice cream afterwards. And it's been extremely hairy trying to keep them seated, i don't even, because i don't mind the moving as i explained. But I think in a restaurant and you've got people walking around with big heavy hot plates. I can't have my children I won't have my children running around and causing either themselves harm or someone else.

So, yeah it's quite tense sitting - we don't sit for long, if you know what i mean, once dinner's done we're up and out. But yeah twice i think it's happened now but yeah we've never really gone anywhere else we don't really go out to eat as a family--

[00:48:05] Interviewer: Do you get to go away at all?

[00:48:07] Interviewee: Not really. We've never been on a plane, um, we've done a couple of holidays here, Butlins, we've tried that and, um, and a couple of nights by the seaside and just go for a couple of nights that kind of thing.

And we do travel up north now and again to visit my husband's parents. Um, and that okay because it's Granny's house - that's not too bad. But if we've ever gone to a hotel it's quite tense because it's you know, Christopher will just say "I want to go home to the white house" because our house is painted white, "white house, white house, white house.."

Carl can't communicate that so we know if he's stressed we just do, you know, do what we do normally just trying to de-stress him and make sure that.. but we very rarely go.

We would love to go on holiday. We would love that, the thought of going to Spain and the two of them freaking out for a week because the weather or the fan or the pool or whatever it is...

[00:49:07] Interviewer: It wouldn't be much of a holiday.

[00:49:09] Interviewee: Yeah, it's not exactly a holiday, is it? So well we'll probably try and do um something again maybe Centre Parks because they

both love the outdoors. Carl's an absolute forest boy. You know Stig of the Dump I call him. Give him a pile of mud, sticks, stones he's absolutely happy so anywhere calm and outsy is-is good for Carl.

[00:49:33] Interviewer: Fabulous.

[00:49:33] Interviewee: Yeah Christopher loves it too. Again you know given the chance to sit down with the iPad and he would do that but-- once he's out he really enjoys it. You know they really enjoy forest school. They go to that quite frequently with school and we do sort of like walks in the woods and stuff so yeah-- we do get out and about and we try - we've been able to do a lot more in the last year or two than we ever had - just because Christopher has started to become a little bit more grown up and I could at least if he was having problems at least then if he was having a problem i could at least kind of start and break down and talk-

[00:50:08]Interviewee: -rationalise, threaten, bribe, whatever. And, whilst I've got my hands on Carl, whilst when they were younger if they both started, I couldn't keep them both safe.

[00:50:15]Interviewer: Sure--

[00:50:16]Interviewee: Do you know what I mean? He was-- because he had no understanding of of that you really couldn't go in that road. With Christopher, I can now say, "Look I know you've got the hump, but you really need to stand there while I deal with this, and then we'll talk." Do you know what I mean? I couldn't-- I've got a little bit more of a leeway with him, so I feel slightly safer out and about, and let's put it this way, generally, if he starts, as long as I've got Carl safe I can deal with him. Do you know what I mean? Whereas before I wouldn't have been able to because he was just a bit of a fireball, and he still is, but it's just a bit more containable.

[00:50:49]Interviewer: And for- You said you haven't had much professional help with their eating issues. In an ideal world, what sort of help would you have liked to have had? Or would you like to have?

[00:50:58]Interviewee: Okay, um- In an ideal world, it would have been- It's really hard because, when you're in the deep, de- despaired time, all you want is someone to walk into your house at that time and-- wave a wand, do whatever, but if you had to do it right, I'll tell you what might work-- um, you know, when I say right, it's what's right for that child then, but really, at that time, it wouldn't have worked, do you know what I mean? It probably wouldn't have worked--

[00:51:23][background noise][doorbell]

[00:51:26]Interviewer: Oh, Excuse me. Just one second. My doorbell's going off, I'll just- I think it's a delivery. Just a second.

[00:51:31]Interviewee: Christmas time!

[00:51:32][background noise - talking to postman]

[00:51:51]Interviewer: I'm back again. It was the postman.

[00:51:54]Interviewee: Yeah, that's Christmas time isn't it? Deliveries.

[00:51:55]Interviewer: So, you were saying in an ideal-- you were saying that someti--

[00:51:59]Interviewee: I mean I would have loved-- there were times I'd have loved to have someone come in and, you know, try to-- say "try this, try that", but I don't really think that that would have worked either because-- [sigh]-- I would-- It was more that I needed a bigger picture, do you know what I mean? Because, at that time, [sigh] I also eh, this'll probably sound a bit confusing, but I know what I mean, I'm just getting to it.

[00:52:20]Interviewer: [chuckles]

[00:52:20]Interviewee: There's-there's part of me.. sometimes Carl will do what I call a running buffet. So he won't eat dinner, but then every five minutes he's at the cupboard wanting some dry cereal, and, you know, the way I was brought up was "generally, if you don't eat your dinner, you don't get your treats," and that kind of- do you know what I mean? It comes down to a bit of my-- and I'm--

I'm not-- [sigh] I-- I've done many things so that-- to make sure that my children have eaten, and I've gone against many of my grains- does that make sense?

[00:52:47]Interviewer: M-hm.

[00:52:48]Interviewee: Um, whereas, I would've probably been a little bit less if they didn't have special needs, then I would have been a bit stricter, um, because-because-- I was a really bad eater, and I remember all the battles I had with my Mum, but I could understand, and I knew what my consequences were and all of that, but it took my children a bit longer to learn that. Do you see what I'm saying?

[00:53:09]Interviewer: Yeah.

[00:53:10]Interviewee: I was probably a little bit more lenient. Um-- So-- but I'm not prepared to stand here and cook four dinners, either. Do you know what I'm saying? For each one of them to go in the bin? So, um-- I don't know if that sounds really harsh, but I suppose that's what I-I-I-I- I don't want, um-- When someone tells me "do this," or "do that," I might not have took to that. Does that make sense?

[00:53:30]Interviewer: M-hm. Yeah.

[00:53:31]Interviewee: I wasn't gonna stand here like I said- If Carl's really not eating something, and I really know he's really hungry, then I would let him have a slice of toast. I would let him have a bowl of cereal. Um-- Because-- but with him, I don't know what else to do. Whereas with Christopher, I can say to him more, "Actually, no, you've already had that today." Um, you know, and I can talk to him about it and I can rationalise with him, but with Carl, I've got no rhyme or reason as to why he stops eating that food, and what I can do to sort it out, and I don't think anybody else would've. Does that make sense?

[00:53:58]Interviewer: M-hm

[00:54:00]Interviewee: Do you know what I mean? Um, and that's not me being the professional parent, or the parent that knows best. If he can't tell you, he's not going to tell anyone else, is he? Do you know what I'm saying?

[00:54:10]Interviewer: No, no. And what do you think is underlying it with them? What, I mean-- When they're sort of- when they're really fussy about food, or-or particularly--

[00:54:19]Interviewee: Well, what the issue is is, I think a lot of it is smell and texture. Look, because Carl can-- Carl can look at a plate of pasta and know that it's not his normal pasta. So I think a lot of it is visual, smelling, and if it's not quite the same shape, if it's not quite the same look, um-- to say because, the pasta really, the gluten-free pasta, it doesn't taste that bad. There's no real difference to you or I, but to Carl there is. So I think it's taste, texture, look, smell, all of the sensory things.

[00:54:51]Interviewer: M-hm, m-hm.

[00:54:52]Interviewee: But I kind of, um- Carl- Carl has got a really sharp sense of smell. He used to be doing his no-noise before I'd even come into the room with the plate of food because he could smell it. And he'd be going "nep, nep, nep," and I'd be like "You haven't even seen it yet! Let's have a look at this," and he would know already that he weren't gonna eat it, so I think smells, for him. Do you know what I mean? Um-

[00:55:13]Interviewer: When they were first diagnosed did you go to Earlybird or anything like that?

[00:55:16]Interviewee: I've done Earlybird, I've done Earlybird, yeah, that was--

[00:55:18]Interviewer: And did they, did they cover anything about eating?

[00:55:23]Interviewee: They did, but do you know what? I can't remember it. [laughs] You know I've probably still got my paperwork.

[00:55:25]Interviewer: Oh, so you can't remember whether it was useful.

[00:55:27]Interviewee: I forget that I'd done it, because at the time I'd done it, Carl hadn't been diagnosed at the time. I was doing it for Christopher. As soon as I got his diagnosis I managed to get on the course quite quickly, so it was not all about him, even though I knew, I remember sitting in my weekly meetings

saying "My youngest son's autistic but he just hasn't been diagnosed yet," and they'd be like, "He's quite young" and I'm like, "No, I know. I already know,"

I already knew with Carl by when he was about 12-14 months. So-- um-- and it just took-- obviously I approached to my pediatrician, and he said, "Let's just give him a little bit longer. Let's wait until he's nearer two-," and I consequently had his diagnosis really early, but when I'd done the Earlybird, the focus was on Christopher, and again, it was more about his behaviour than it was about his food at the time. Even though it was covered, I'm sure. I don't remember much of it to be honest.

[00:56:21]Interviewer: Sure, no, that's fine.

[00:56:23]Interviewee: it was more about his behaviour and his speech.

[00:56:25]Interviewer: And would it be useful to have things like groups that were just around sort of eating problems with kids with autism, or like-

[00:56:32]Interviewee: Yeah. Definitely. If there isn't a service that Kaleidoscope or dietitians can't provide, just another sort of drop in service, like I said, if someone had come- You want someone to come 'round your house and help you at any given time. In any of it, not just food, when they're having a meltdown, when you can't get them to bed, you just want someone to come in and help you, but in hindsight that's probably not always going to work. That's what I'm saying with the food, but if that service was available? Yeah, I'd have tried it, and I think there would be a lot of parents that would benefit from that. To have someone come in and spend an hour with them at mealtime, and go through how, you know, they'll be placingthe food and you know like using bowls and doing the desensitisation, I think it's called, isn't it?

[00:57:14]Interviewer: Yeah.

[00:57:15]Interviewee: So, you know, maybe that would help some parents and- and maybe make them feel calmer about the whole thing, so that they will treat you differently, because a lot of it boils down to your stress as well sometimes, because, like I say, I don't really- I feel bored. I feel like all I've done is cook chicken nuggets, sausages, and the odd fish finger, for about five years.

Do you know what I mean? So- but, that's me. It's boring to me. It's not boring to my kids. They're happy. [laughs] So, you know, [sigh] yeah, any kind of advice, anything, I think a lot of people would do, if they could.

Just to try, to see if it could help them approach it in a different way. For me, I feel like I'm a little bit over it now. I feel, as long as my kids are eating-- a bit of fruit and veg every day, if it doesn't quite match the five, you know, I can live with that as long as it's about four, and they're getting a bit of protein and a bit of calcium, I'm kind of leaving it there. Do you know what I mean? I'm always trying to get something new down them, you know, and offer, but I don't stress over it as much as I used to. I will leave it a bit before I then try again. Do you know what I mean?

[00:58:18]Interviewer: Last question, um, is-- Have you ever tried any of the sort of special diets or supplements for your children?

[00:58:25]Interviewee: Um, you know, the only one I would do- I would just do the- You know the *Abidec?*

[00:58:30]Interviewer: M-hm.

[00:58:31]Interviewee: You know, because I was worried about various intake, I would do the old squirt of *Abidec* to kind of make sure they'd get a little extra vitamins. That was when they were probably about three, four, five. That kind of age. But no, I haven't. The only thing I've ever given Christopher is the calcium liquid. Um-- But no, I've never tried any- because they're really fussy about what they drink, Christopher only drinks water, doesn't drink juice. Um-- Carl will only drink water, or he'll drink any of my-- my cup of tea, or he'll come over and drink my hot drinks, and we make him hot chocolate [stuttering] oh, sorry I forgot that. He likes a hot chocolate, but um-- they don't really do milkshakes and things like that so, if I probably-- I've never tried to make up like a-- are you talking about one of those shake things, where you get all your goodies in it?

[00:59:16]Interviewer: Yeah, yeah. Or--

[00:59:17]Interviewee: Meal replacement type-things?

[00:59:19]Interviewer: Or things like gluten-free and milk-free diets and things like that, as well. You know they have the sort of special diets that some people try for autism.

[00:59:26]Interviewee: Just for autism, no. I've never embarked on one of those-- Just because they're so fussy. Even now, Carl won't even eat gluten-free pasta because it's in my house for a different reason - Christopher's IBS, but he won't eat it. So I've never really tried. No, no, I've just stuck with what I've done. Now, I feel like they get kind of vitamins, and it's just the calcium- and the protein I'm worried about.

[00:59:54]Interviewer: Fab. Okay. And, is there--

[00:59:55]Interviewee: Does that sound okay? [laughs]

[00:59:59]Interviewer: No, it's that--

[1:00:00]Interviewee: Not "is it okay for the purpose?" because I thought-- It's making me question like, my whole childrens' eating, then. Do you know what I mean?

[1:00:05]Interviewer: Do you know what? Do you know what? If you're-- [sigh] So, you know- I'm one of the dietitians at the hospital as well, and if you are concerned about their diets, then you can go back and ask for another appointment with the dietitian. That's always what the services are there for.

[01:00:18] Interviewee: Okay fine.

[01:00:18] Interviewer: And-

[01:00:20] Interviewee: [coughs]

[01:00:21] Interviewer: -it's sort of like my purpose of like doing this is not really to give you any advice or anything so I can't give you any advice based on what you told me but I think that, and I think that you seem to have quite a sensible approach to their eating and I think it is-- if for any parent that's got any concerns about their child's eating then asking your doctors to refer to a dietitian

for a check up is perfectly fine and even if they've told you in the past oh, this is fine, children's needs change as they get older-

[01:00:49] Interviewee: [coughs]

[01:00:50] Interviewer: -And they need different amounts.

[01:00:52] Interviewee: [coughs a lot]

[01:00:55] Interviewer: [Laughter] so children's needs change and so it's fine to go back and say "well actually can I have another appointment?" And that's completely that might be something-- you want to do if you are concerned.

[01:01:07] Interviewee: Do we need to go back to the doctor or are we going to need to go back to Kaleidoscope?

[01:01:12] Interviewer: So the doctors make the referrals so the doctors sort of pay for services I suppose if you think of that way. So it would be a matter of asking your GP or your paediatrician, whichever one you're seeing at the moment- and ask them say "can you refer me to the dietitian because I'm concerned about whether they're getting enough of everything?"

[01:01:28] Interviewee: I mean I have tried yes I mean I have done it I've done the food, specifically with Christopher he is still seen by the hospital for the IBS yes.

[01:01:37] Interviewer: Yes.

[01:01:37] Interviewee: And I've done the food diaries and with him I've gone into a bit more intricate because of that, with Carl, I've kind of looked at it a bit more loosely then. But and I have done like as i say putting the bowls out, but it's when they flatly refuse, you know what I mean you just kind of, it just takes the.... you know - God what's going on [laughter]?

[01:02:03] Interviewer: Well there's different people so let's-

[01:02:03] Interviewee: In the end what's the point you know what I mean?

[01:02:05] Interviewer: Yes.

[01:02:06] Interviewee: Because it will just-- yes it's never worked for me yet and that's it.

[01:02:09] Interviewer: And at school as well then there's the occupational therapy services and things attached to Brent Knoll so you can ask them as well you can say is there anything else you can help us with on visiting?

[01:02:17] Interviewee: Somebody does get seen by the OT just because of his kind of other sensory issues-

[01:02:22] Interviewer: Yes.

[01:02:22] Interviewee: -And we did discover that he did need, for instance I got him a smaller knife and fork. Not that he was using it be terribly big, but I just got him a smaller one just so that we could try and practice some of like his knife and fork skills and things like that.

[01:02:38] Interviewer: Okay.

[01:02:40] Interviewee: But yes I have spoken to the OT about various different things but okay so as a dietitian it's not terrible? I don't need to go running for the hills [laughter] because they're eating good enough [laughter]. I'd love them to eat a little bit more protein, a little bit more.. not chicken dippers basically but I've even done my own ones, done my own chicken breast wings and battered them. Carl just wouldn't touch them. Christopher might - we've got a little bit down his neck before but his not-- yes it kind of gets more splacating business than it was he really likes them do you know what I mean?

[01:03:15] Interviewer: I mean it sounds like you've got the right attitude of being sort of chilled out about it and not pushing too much because I think with kids with autism if you push them too much then it can backfire.

[01:03:24] Interviewee: Yes it is yes.

[01:03:25] Interviewer: And it is as you found out as they get older and you can reason with them a bit more sometimes you can sort of have more successes with trying new things. But what I can do is I can-- yes I mean if you ask for a referral to the to the dietitians for Carl, then the dietitian can also see

whether he can be referred onto there's at kaleidoscope the OT's are doing some sessions around food as well.

[01:03:54] Interviewee: But will the dietitians be at Kaleidoscope is there-- that the doctors will refer me to.

[01:03:57] Interviewer: Yes.

[01:03:58] Interviewee: Yes okay fine okay.

[01:04:01] Interviewer: So I suppose is there anything else you want to tell me about either of your child's eating or how it affects you as a family anything that you haven't said?

[01:04:11] Interviewee: Um not really I mean I think I've given you the rough idea, you know, we've been round and round and round we've tried lot's of -- after I've once have found what I knew they would eat, I just stuck to it.

[01:04:22] Interviewer: Yes, yes.

[01:04:23] Interviewee: Do you know what I mean? Because that they not eating what I want, what I'd like them to eat would be my home cooked meals. But then I-- but when I do a casserole or something like that I would love them to eat it, just because they're fresh, properly cooked and the fact, I don't really llike sausages, but its the only thing I can get down their necks. But the chicken (eergh) I would really dearly love them not to eat that but the fact that they eat their raw fresh vegetables every day and that kind of thing then I just kind of go with that you know what I mean?

[01:05:00] Interviewer: Yes.

[01:04:59] Interviewee: I think I've given you the rough idea of how they eat and-

[01:05:03] Interviewer: Yes.

[01:05:04] Interviewee: -My attitude towards it and not to say that I've given up because I haven't but yes I'm aware that I've got a longer road to go with Carl.

[01:05:12] Interviewer: It's pick your battles.

[01:05:14] Interviewee: Picking my battles.

[01:05:16] Interviewer: [Laughter]

[01:05:18] Interviewee: Yes so no I don't think there is, now I think I've it's quite tense, we don't go out, we've managed to do a Harvester twice [giggles] we tried the carvery once and we had to leave there - they just didn't like the environment -- we didn't even get as far as the food it was more about the environment and then yes we just-- but then we're quite homeward bound anyway you know, we all like being at home, do you know what I mean? We're quite happy when we are here as well we've all got our little attachments to home we all feel quite safe when we're back all together-

[01:05:48] Interviewer: So-

[01:05:48] Interviewee: -That we've got used to. So it doesn't bother me that I can't go out to restaurants is what I'm saying.

[01:05:53] Interviewer: Yes.

[01:05:54] Interviewee: You know what I mean?

[01:05:54] Interviewer: Fab fab. So those were all my questions, do you want to ask me anything?

[01:05:59] Interviewee: No I don't think so. No.

[01:06:01] Interviewer: So thank you so much for your honest answers and I think it will be really useful for my work

Appendix 20: Participant 4 transcript

[00:05:41] Interviewer: Okay so, um, first question just to start off with. Um, who-- who is in your household?

[00:05:46] Interviewee: It's myself and David and his younger brother.

[00:05:52] Interviewer: Okay so, um, and David is on the spectrum, is that right?

[00:05:56] Interviewee: Yes, he was diagnosed in July 2015.

[00:06:00] Interviewer: Okay. Can you tell me a bit more about him and how his, um, autism affects him?

[00:06:03] Interviewee: Yeah. Um, well, he's easily very overstimulated, has, um, um, I find that-- I have to create as calm environment as possible and, um, he's easily—easily overwhelmed and easily distracted by things, um, and he has obsessions and fixations on things and, you know, collects things and he's very protective over his space and he tends to, um-- he has this sort of this-- this bag-- he's a little kind of like a bit of a bagman actually. He puts all his things that he wants to protect in bags, they sort of move around the house with him because he doesn't want anybody touching them, contaminating them, and just lately he's been leaving things in packaging and, uh, you know, things that he's been bought recently, he doesn't want to open them, he wants them left in the packaging. Um, so extremely sort of obsessive, um, very, um, very territorial and, um, very, um, um, uh, very up - lost my train of thought then.

[00:07:22] Interviewer: [laughs].

[00:07:22] Interviewee: But extremely just, um, you know, he needs his own sense of his-- of himself and his belongings and we don't leave an ideal accom-- accommodation, it's quite, uh, you know, um, we don't have enough space so maybe it's just sort of-- it might be part of that but it's probably more to do with his, his autism and just wanting to, you know, protect his own-- his own stuff and having-

[00:07:49] Interviewer: Mm-hmm.

[00:07:55] Interviewee: -his space. Um, and he has this extremely str-- he has extremely controlling behaviour as well and he will often, um, if he's knocks into him or he's been accidentally touched he's constantly tapping us back, um, tapping his brother constantly, um, he's very, um, uh, has extreme reactions to smell and, um, noise, um, and gets extremely easily distracted and gets distressed if there's um some background noise so it's like he's very dominating and he has to be that-- he has-- he has a great need to be in control of everything.

Um, and he doesn't like when it we-- when you know, we've got to respect his space and otherwise it's you know, he's screaming, he's throwing things, he's, um, you know, having panic attacks so extremely controlling, protective behaviour, um, and everything has to be on his terms, um, and it's extremely-- it's extremely difficult to reason with him-- virtually impossible to reason with him.

[00:09:11] Interviewer: Okay-

[00:09:12] Interviewee: Um.

[00:09:12] Interviewer: -and how old is he now?

[00:09:12] Interviewee: Yeah. um, did that-- have I sort of deviated from the question or what?

[00:09:18] Interviewer: No, n,o no. That's great. How old is he? Remind me how old he is.

[00:09:22] Interviewee: Seven and a half. He'll be eight in February,

[00:09:26] Interviewer: Okay.

[00:09:28] Interviewee: February.

[00:09:28] Interviewer: And tell me a bit about his, um, eating problems.

[00:09:29] Interviewee: Oh, um, extremely-- extremely fussy. He all-- he'll go through phases of wanting to eat the same food over and over and over and

over again. Um, so he'll go through phases of wanting the same meal over and over and over again, then he'll go back to another sort of common meal that he used to eat but it's very difficult to introduce new foods to him, he's extremely sort of set, um, and odd about textures for example, I mean, he really likes having pizzas but, um, I have to cut them in such a specific way and if there's anything, um, if there's a bit of melted cheese that's fallen off the side of the pizza, he will get very upset by that and I'll have to cut it, you know, make it all very neat- make all the edges very neat for him, um,

and he's been very difficult about taking his omega, um, his omega supplements which is, you know, very important but he's- he does a lot of regurgitating with sort of, skins, um, so he'll regurgitate his vitamins after, um, his omega, vitamins so, um, he doesn't like the texture of those, and recently with apples, he doesn't like it... suddenly... he goes from one aversion to another, he always had some sort, um, sort of strange reaction to sort of textures like now it's the skin of apples. I don't know. I know that, um, I know sometimes he used to be-- I think he gets panics about choking or something. Um, so maybe it's to do with that, maybe he is, uh, has a fear that he's going to choke so maybe it's-- it's that but I'm trying to sort of rationalise it while you know, uh-

[00:11:22] Interviewer: So how doe- how doe-

[00:11:23] Interviewee: I know he gets used to-

[00:11:25] Interviewer: So how does he react to them?

[00:11:26] Interviewee: Um, and you know he has um strong reactions to smell and sort of be able to- he'll look at some food, if he doesn't like the look of it he's not going to touch it at all so, um, and the smell-- the smell and the way the food looks, is just sort of very, um, has strong reactions to him as to whether he will actually engage and try some new food. Um, so yeah. So if it's not to his liking then there's no way he's going to try it, um, so that's extremely difficult, you now, trying to introduce new food to him and definitely just-- he's very habitual in his eating habits

and he'll tend to-- he doesn't really like big meals. He'll tend to have lots of small meals throughout the day, um, he likes to graze a lot and I think that's a way of-- because he can't sit-- he finds it very hard to just sit still and eat a meal, he'll need.. But I do have larger plates of food for him you know, trying to get him to eat-- you know, set meals and lunches. Sometimes that will work if he's, you know, watching a screen but he's always-- he's got to have-- he's got to be watching a screen, that's what I found works with him. If he's watching something then he'll engage a bit more, stay still but otherwise he's always on the go, always moving when he's eating. Um-

[00:12:56] Interviewer: And is his eating different in different places like at school? It- it does he have the same eating problems?

[00:13:03] Interviewee: Yeah, I mean, he'll reject-- reject a lot of-- lot of stuff. Um he's been home-- I've had to take him out of school since um since Easter, April this year.

[00:13:11] Interviewer: Yeah, of course.

[00:13:12] Interviewee: He couldn't cope he was fully overwhelmed, um, so I'm trying to look at some other alternative provisions in the meantime but, um, homeschooling for now - which is exhausting!

[00:13:21] Interviewer: Mm-hmm.

[00:13:26] Interviewee: Um, but yeah he- he's got an aversion to butter, he developed straight-- suddenly he'll just go off a food from-- he'll really like it for a long length of time like he'd have butter on everything and now he has strong and angry reactions to butter. If he feels-- if he thinks-- he detects or smells his food and he'll get quite a bit paranoid actually that there's butter in there. Um, or he'll get-- he'll think that, "You're really trying to trick me and there's butter in there" and even though you know, there isn't and there clearly isn't, um, but he's very, um, odd, he's got this fixation about butter now and, um, you know, nothing can have butter on it, um--

[00:14:08] Interviewer: And what will his-- what will his reaction be if he does think there's butter in something?

[00:14:11] Interviewee: Extremely angry. He'll scream, he'll throw things, he'll throw the food.

[00:14:16] Interviewer: Okay.

[00:14:16] Interviewee: Yeah, yeah.

[00:14:17] Interviewer: And what-- if someone was watching a mealtime, what would it look like?

[00:14:22] Interviewee: Uh, extremely disruptive, very chaotic, um, he's you know, um, we sometimes go to *Nandos*, um, he's very volatile, very unpredictable so sometimes he'll be, um, you know, screaming, um, he's upset about something and I have to try and like work out what has upset him or, um, he'll have the set the same sort of set food that, um, that he likes at Nandos. He moves-, he likes to be-- he's very messy, he makes so much a mess, you know, he's, um, he's piling on- he likes a sort of salad cream dressing that he has with some halloumi.

He mixes that into his rice that he sort of-- he only uses his fork he can't use a knife then he's sort of, you know, very clumsily shuffling his food all around on his plate, it's going all over the table, um, and, um,

um, you know, he's just you know always got this sort of agitation about him always sort of, um, you know, um, you know, something his-- his brother can upset him you know, he's always upsetting him as well, um so he's easily provoked by, um, by who's around and also by atmospheres too and smells.

[00:15:43] Interviewer: What impact do you think his eating problems have on him?

[00:15:48] Interviewee: Um.

[00:15:49] Interviewer: Do you feel they any impact on his health? Or on his socialising or anything?

[00:15:54] Interviewee: Yeah. He doesn't he doesn't have a particularly balanced diet, he craves a lot of sugar as well, a lot of sweet stuff and then if

he's had some sweet stuff, he will tend to just want to eat that nothing else and he just get a constant craving for sort of chocolate and sweet stuff and you know, then I feel like--

well-- actually, I got really concerned because I thought he has such um extreme mood reactions. He-- he-- definitely, he's mood's affected by what he eats and I've noticed that he'll get extremely, um, start having a panic attack and screaming if he goes for-- if he realises he's hungry but he hasn't been able cos he's been distracted by lots of things so he's not able to say, um, you know, when he needs, you know, I'm always, you know, I've always got snacks around for him but then sometimes, but suddenly he'll have this huge meltdown because he's realised he's hungry but he hasn't been able to eat enough or get enough nutrients so then he's screaming

and then I find-- once he's-- I've managed to get a bit more food in him other than just little snacks of, you know, grazing bits and pieces and he's eating in a more satisfactory meal, um

But, he needs a lot of encouragement with it you know, monitoring, supervision with it-- you know, prompting, reminding that, you know, he's got to try and finish all the food on his plate and i'll have to, you know, its a very sort of, carefully orchestrated event where I have to put the screen on, so he's sort of, he's eating but then, um, I'm constantly reminding him to just to eat, to try to eat as much as he can on his plate and then that in turn will have a-- you know, once he's managed to get you know a better sized meal with more varying nutrients, it has a more stabilising effect on him - yeah

Oh... and he forgets to drink and then that-- he won't be able to say sometimes that he's thirsty, he just needs to drink you know and he'll have extremely violent, angry, aggressive behaviour because he's forgotten that that's what he needs to do or, you know, there's so many sort of stimulus in his environment that he's just--

so its you know, its really exhausting to manage that because, um, you know, he has extreme reactions if he hasn't eaten, or if he hasn't maintained his

proper fluid intake throughout the day and eaten well, then it will just sort of erupt, in some way, with either throwing things, screaming, um, because he's not always able to sort of, say-- so he needs you know constant guidance and supervision with that.

[00:18:38] Interviewer: What impact does his eating problems have on you?

[00:18:41] Interviewee: Its exhausting. I am so drained and so exhausted. I you know-- if i just-- my energy levels, you know, you know, its you know, its very intensive-- its very intense you know, he's because its almost like having a baby-- I thought that the other day - it's like having a little a baby that never grows, you know, who needs that constant-- who can't really do anything particularly for themselves, you know, because I do all his-- his care as well he can't, you know, he can't manage the toilet, he can't manage cleaning this teeth, he can't manage dressing, you know,

and then I'm supervising all the meals and his whole - just trying to monitor and get all the nutrients that he needs throughout the day constantly or else, you know, I mean, he'll happily binge on you know, sort of sugary things and just help himself to things, you know, snacks of chocolate and things like that, which, you know, I avoid having in the house but, yeah, I mean, its a constant worry, you know, it's a constant anxiety to me.

[00:19:48] Interviewer: And you've got-- I mean, he's got a lot going on. From like with all of the other things going on. Is the eating quite-- like -- quite a big priority in, in sort of what affects you and him or do you think its lower down? I mean, where would you put it on the priority thing?

[00:20:04] Interviewee: Its a priority. I think its a big part. He likes his food but he just forgets to, you know, he'll just snack or he'll just forget to-- I constantly have to, you know, remind him that everything, um, sorry what's was your question again?

[00:20:20] Interviewer: I supposed its sort of, if you're like prioritising his different issues, do you find that eating is one of the big ones for you?

[00:20:28] Interviewee: Yeah. It is. Yeah. Cause it definitely affects his mood and his behaviour, um, yeah.

[00:20:34] Interviewer: Okay. And you had sent me some photos and you sent me some pictures of some apples on a plate, I think, that he had been eating and what was that sort of telling me?

[00:20:43] Interviewee: He likes to eat everything with a fork as well. Even pieces of fruit, even crisps, he won't just pick them up with his hands, he'll use a fork, so you generally have to have everything with a fork - I don't know. He just doesn't want to get his hands dirty or touch the food or something - he's got this little compulsive, washing his hands recently, um, so he'll need a fork to eat with and - sorry what was your question again?

[00:21:11] Interviewer: I was asking-- so you sent me a picture of him of some apples on the plate. So it was really like, what were you trying to te-- like, why did you choose that picture? What was important about it for you?

[00:21:22] Interviewee: Well, it felt that, um, he has-- he likes these apples slices and also you'll see that-- the apples skins have been regurgitated, he spits a lot, so he spits a lot of food out, you know, dribbles it out of his mouth - wherever he is - and he does a lot of spitting as well and I just want, you, to to me its sort of connected, constantly spitting and this was a demonstration of me having to cut the apples up. He needs a fork to eat apples with, um, he has, you know, regurgitated the skin, you know, on the plate, he spat out some of the apple skins.

[00:22:04] Interviewer: Mm-hmm. Okay. Then the other picture that-- I'm-- I picked up from your email was of-- I think your two boys with, um, with pumpkins. So tell me about that.

[00:22:17] Interviewee: Yeah. They got very-- David got very obsessive with collecting pumpkins during the Halloween and he used to force me to go to the shop to get pumpkins for him. So he got a quite a large collection of pumpkins and he got fixated on, sort of wanting to, you know, cut the heads of the, the top

of the heads off the pumpkins, so and he enjoys doing that activity, you know, so it was a way of him engaging with food.

But, it's a very sort of-- [sigh] how would you describe it, in a sort of-- I don't know, it just because the pumpkins became a big fascination for him. And he did a bit of the scooping out, but then he got funny about the texture, and yeah, it was more just about sort of as an example of, you know, sort of, his obsession with collecting, really, yeah, and again and it reinforced the sort of habits that he has with with food as well, you know, it, you know, it is almost like a sort of mirroring because, um, he going through phases with his eating, with his obsessions and his collections. Its almost a bit like, um, you know, when he is-- with his food obsessions, he goes through one phase of eating the same sort of food and then he'll go off that and then it will be another phase and he would go back to that, you know, phases of eating the same sort of food all the time.

[00:23:53] Interviewer: Mm-hmm. Okay, and I think you said there were some others that you sent me but I haven't picked up. I don't know, do you remember what they were of, or--?

[00:24:01] Interviewee: Yeah. Let me just look inside my, um, is your email, your messages came through my iCloud accounts i don't know why they do that but I don't often check my iCloud account but maybe, I have a feeling when I sent those pictures it must have been through my iCloud account. I'm just checking, um, sent, yeah, okay. Yeah, no, there's three pictures and maybe they didn't all go through then.

[00:25:00] Interviewer: Okay, That's no problem.

[00:25:03] Interviewee: You said you received three, yeah?

[00:25:05] Interviewer: Yeah, I think two of the were the same plate of apples-

[00:25:06] Interviewee: Oh, right.

[00:25:08] Interviewer: -and then one was with the pumpkins.

[00:25:10] Interviewee: Oh, right. Okay. Yeah, the others obviously didn't get sent because I just-- I did it directly through my photo app. I have to get through and see-- I sent now.

[00:25:21] Interviewer: No problem. When you do want to send anymore through-- what's quite useful, if you can give them like a caption. So if email to me and then tell me like, a sentence or two about like, why you chose them or what, you know, what you think about the picture, that's really useful.

[00:25:39] Interviewee: Okay. Yeah. I can do that.

[00:25:43] Interviewer: Okay, so, um, what else was I asking you, um, so, and how does it affect his brother? Does his eating affect his brother at all, do you feel?

[00:25:52] Interviewer: Um, yeah, because he's copying him. He'll, um, he'll quite often copy some of David's behavior and he'll have the same sort of reactions to him. The thing is, his younger brother is also being assessed for ASD - we're trying to work out now, how much of it is copied behavior and how much of it is you know possibly part of his own-

[00:26:17] Interviewer: Yeah.

[00:26:18] Interviewee: -development. So, yeah. I mean, he'll-- he'll pick up things and you-- you know, he looks to his older brother and yeah, tends to sort of, copy a lot of what David does. But having said that, Daniel's diet is even more restricted. So, you know, he had very strong reactions to smell and food textures. So, um, yeah. It's hard to know what-- you know, what part of it is his own possibly being on the spectrum and what part of it is the effect of David.

[00:26:57] Interviewer: Okay, sure. And what professional help have you had or non-professional help I suppose. What helped with David's eating in the past?

[00:27:11] Interviewee: Um, I find-- by putting a screen on, you know, by putting a DVD on for him or something like that ,which I-- you know, it saddens me to resort to that but I found it - so he can't sit at the table, you know, he can't

sit still at the table and I've tried in vain to make that work and maybe now it has become habitual, with the screen but-- or maybe the association of that now - eating and looking at screen, I would, of course, rather that didn't happen, but I just, you know, for me it just became a very desperate measure, because I've been-- I've been very worried about his eating and I just I noticed that he could focus better and comply to complete more of his meals, than when-- I didn't have any screen there for him,um,

um, and help, um, haven't really-- I've-- he did a circus group. I mean, the thing is, he's capable of doing all these things, you know, probably, you know, dressing himself but I think it's very much a very sensory thing, he's so distracted by his own thoughts, his own being, in his head or, you know, the environment that extremely hard for him to sort of just filter out all these sort of things, you know, um, so what helped in terms of his--

[00:28:43] Interviewer: And you've recently had a dietitian's appointment. Is that the first sort of, professional appointment you've been to about his eating or if you had--

[00:28:50] Interviewee: I think maybe-- it has been actually, yeah.

[00:28:55] Interviewer: Was that something you asked or was that sort of the doctor--

[00:28:59] Interviewee: Yeah. It was something I got concerned about because of the constant regurgitating. Yeah.

[00:29:05] Interviewer: Okay. And previously, like, so his eating has been going on for a while. So have you ever brought it up to the doctors or nurses before or anything?

[00:29:13] Interviewee: Only when he was very-- a lot younger. I went to-- I had a consultant-- hospital consultant appointment around his, um, his food. Um, because he had, you know, he had bad colic and then he was an extremely fussy then. So they made some recommendations. That was a long time ago. That was sort of the last sort of dietitian appointment, not-- you know, probably about four years ago.

[00:29:39] Interviewer: Okay.

[00:29:40] Interviewee: Um, so this is the only time sort of since-- uh, yeah.

[00:29:43] Interviewer: So has it, has it occurred to you to ask for more help or is it something that you just don't really know where to go?

[00:29:49] Interviewee: Yeah. Not really aware, where to go and and how to ask for help -- the thing is, its also-- he has so many issues and there's so many difficulties but, you know, sometimes I'm just sort of ploughing ahead, just sort of crisis management, you know, that's what it feels like. Crisis management with, um, with his behaviour.

[00:30:09] Interviewer: And I did you have anything like, did you go to any groups or anything when he was first diagnosed? Did you have Earlybird or anything like that?

[00:30:18] Interviewee: He was diagnosed when he was six.

[00:30:21] Interviewer: Okay. So not that long ago.

[00:30:23] Interviewee: I did get invited to some parenting, some Cygnet groups via ASD outreach.

[00:30:25] Interviewer: Yeah.

[00:30:26] Interviewee: I couldn't make them because of childcare-- because of my youngest son. So I didn't have any childcare in place. So, I found it very difficult to access these courses, um, you know, without, you know, childcare, you know, that's always been the problem because it's, you know, they're extremely needy-- they have extreme needs, you know. So it's very difficult, it's been very problematic to try and find the right school environment for them and the right kind of childcare and that, you know, being very aware of not trying to drive, you know, that they've got a high-- high anxiety. So being comfortable and sure of the right, you know, provisions for them and needs to be met which, you know, so far, its been a very difficult journey to achieve that.

[00:31:15] Interviewer: In an ideal world like without those sorts of issues around NHS funding and all of that. What sort of professional help would you have liked to have had when he was younger with his eating or would you like to have in the future?

[00:31:31] Interviewee: You know, I'm just -- it's a question I've been asking myself a lot lately and I think-- I would have really liked something like-- there's this programme called "The Sonrise program", um, I don't know if you know of it.

[00:31:46] Interviewer: Yeah. I've heard of it.

[00:31:47] Interviewee: Yeah. And I was just watching a video about that the other day and it made a lot of sense to me about getting back to doing-- um, they need one-to-one support and a very sort of supportive environment and I feel like a lot of these-- they can't particularly be overcome but they can sort of be supported where you do-- they do-- the intensive one-to-one play therapy. And I think a lot of it-- a lot of that stuff seems to go-- it seems to be very rooted in sort of, emotional turmoil of stuff and I don't know, just finding ways to be able to sort of-- you know, ways into their feelings, um, I just thought -- this sort of-- this Sonrise programme seems quite interesting in terms of-- I think ideally, if I could - go back in time with David and had-- people come into our home-- something like the Sonrise Program and worked one- to-one through play therapy because they-- I found quite often to connect-- the way to connect with David is through play, you know, but I can't be constantly playing with, you know, it, you know, being a parent that, you know, we've got so many things to do, so many chores to do so but you know. So many demands on us. Especially being a single mother. Finding the time, you know, to manage that by myself is very difficult but I say-- I say a key is through play. Play therapy to me seems like if I had earlier interventions with, with that, with that being offered, you know, in the home, I think that would really help - be a tremendous help actually, and it's something that I'm trying to access now. Yeah.

[00:33:42] Interviewer: You almost need to sort of super nanny service don't you?

[00:33:44] Interviewee: Yeah, yes, yeah, exactly, yeah.

[00:33:47] Interviewer: Somebody that could come in and really, really help, you know, hands-on stuff.

[00:33:51] Interviewee: Yeah. Exactly. Yeah. That's, that's the thing-- that's the key to make, you know, to make a big difference.

[00:34:00] Interviewer: And you said before like it was difficult--

[00:34:02] Interviewee: Actually, it's-- the home is very important. The home environment and it's so important to David, you know, he feels, you know, they need to get a real feel, sense of their roots and, you know, where their space is, and that they need that one-to-one interaction and I think that can-- over the long term the more one-to-one in terms with - in line with their needs and following their interests, through play therapy I feel-- a way into them. To help their-- healing and understanding.

[00:34:38] Interviewer: You said before it's difficult to attend groups in the past?

[00:34:41] Interviewer: Yeah .

[00:34:42] Interviewee: If in Lewisham we put on groups for parents around eating problems and autism. Would that be something that you feel would be useful or would it be just too difficult to attend?

[00:34:54] Interviewee: I think for a lot of parents it can be difficult, it would be difficult to attend unless there was sort of provision, some creche or childcare provision, um, you know, working with with children as well so some parents who aren't able to access this, you know, could access it. Because, you know, it was, you know, people, people in a creche where they understand these, you know, autism.

[00:35:22] Interviewer: Yeah.

[00:35:23] Interviewee: Um, you know, otherwise I think it is very problematic in terms of me being able to access that because as I said, you know, with their

very complex needs it's, you know, and also managing all the obstacles, you know, on the journey, on public transport, you know, I've had so many, um, panic attacks just, you know, on the buses. And, huge meltdowns and very, you know, they're very anti-social and then people are very hostile to them on the bus. And it's just a very negative and extremely draining experience.

[00:35:56] Interviewer: Well, I can imagine, hmm. And how about online support-- so did you-- did you look up-- do you-- are you somebody that goes online and looks up sort of help for different things or is it--

[00:36:07] Interviewee: Yeah, I do and -- but I feel very overwhelmed when I look online. I find it very, a very, exhausting process looking online and, you know, there's so much stuff that you read online and I just feel that if it's not so helpful - it's more abstract and I definitely think, you know, working in a more physical realm is, is best, you know, because you're dealing with very sort of physical behaviours, you know, and I just feel that, yeah, online I wouldn't really get-- personally wouldn't get on so well with that.

[00:36:43] Interviewer: What about if like in Lewisham there were sort of pages that had like little videos on different aspects of sort of managing problems and, and sort of, you know, and more, sort of Lewisham based thing. Or, even an online support group for parents or something like that, would that-

[00:37:00] Interviewee: Yeah, may be an online support group, um, yeah, yeah, yes, something like that. But, you know, have-- you know, I belong to quite a few these online for-, you know, support, forum groups and-- yeah, I find it-- I find I actually-- I end up wasting a lot of time because I'm, you know, I'm reading all this different information trying to, you know, all these different sort of ideas, they are all sort of coming at me and, um,

[00:37:28] Interviewer: Sort of information overload.

[00:37:30] Interviewee: , yeah, it's like information overload, and I think this is what a lot of people are suffering from actually at the moment, you know, being in this tough information age where we're just sort of bombarded with all these

sort of different ways of managing things and in the end you just get very overwhelmed and it's, um, you know, a huge maze and, yeah.

[00:37:50] Interviewer: And for, sort of-- so a slightly different question but, when you go online or-- or-- or when you're sort of doing research about autism and eating. Have you thought-- have you tried any of the sort of special diets or supplements and things like that? But, Is that something that you read about or is it something that you're not really aware of?

[00:38:08] Interviewee: Yeah, I go onto this, um, there is this, um, UK's Parent Support Network called "Arnica" and, you know, they've got lots of advice and sort of ways of, you know, a lot of people offering their interpretation, you know, parent support group.

Um, but it's very boggling and then I find well I have to research around that. And then if something else is mentioned then i-- it's very time-consuming having to constantly sort ofresearch out stuff, you know, when I got the, you know, the demand-- their demands as well and, yeah, I have-- don't have a great deal of time myself, you know, and I don't have-- well, I don't have any time to myself, you know, it's all about my children's needs, yeah.

[00:38:49] Interviewer: And have you tried-- have you, have you, do you give David any supplements or anything like that? Or do you give him-- do you have-

[00:38:55] Interviewee: Yeah, I do, he likes the *U-cubes* now.

[00:38:58] Interviewer: Uh-huh.

[00:38:58] Interviewee: Yeah, he was-- he used to swallow vitamins but he doesn't like swallowing vitamins anymore, he won't swallow whole capsules or anything but he'll-- he likes-- again, they're sugary, so he likes those, yeah.

[00:39:10] Interviewer: Well, the, the, the *U-cubes*, how do you -- is that like the letter U and then Q? What is it?

[00:39:16] Interviewee: Yeah, U then a middle hyphen dash.

[00:39:18] Interviewer: Uh-huh.

[00:39:19] Interviewee: Yeah, and then Cubes. He has those every day.

[00:39:20] Interviewer: Okay. And they're multivitamins. And they're specific like autism-related vitamins or they just sort of children's vitamins?

[00:39:31] Interviewee: No, they're children's multivitamins minerals, yeah. Vi-, I think they're *Solgar*.

[00:39:38] Interviewer: Okay.

[00:39:39] Interviewee: So they're not-- they're not aimed at autistic children, but, you know he's-- yeah, it's the only one I can get him-- it's a gummy. It's the only one I can get him to take.

[00:39:46] Interviewer: Okay. And how about, I mean, do you have him on any special diets? Do you restrict his sort of intake of particular things because of his autism or do you just try to vary it?

[00:39:58] Interviewee: Well, I try and avoid, you know, I try and avoid the sugary stuff, the chocolates and, you know, any sort of snack food, I try and avoid that. But, you know, he'll start screaming out for it and when we're out in the shop-- I just sometimes just give in, you know, because it's exhausting dealing with this constantly. But I find myself still giving in sometimes, um, and, uh, what was the question again? Sorry.

[00:40:26] Interviewer: It was whether you've sort of -- whether you've put him on any sort of special diet for his autism other than--

[00:40:31] Interviewee: Yeah, I mean, I try and avoid -- I think, you know, he had severe colic and he had, um, as a baby, and then, um, until the age of three he was pretty much drinking formula milk most, most of the time. And I feel like, he's, he's, you know, he's gut-- it's been destroyed a bit so I try and-- you know, he doesn't have dairy milk. I've cut that out. And he also suffered with a lot congestion. And I find when he's consumed-- had too much dairy, he gets very congested and can't-- can't sleep very well at night at all. And I've also had to invest in one of these HEPA filters, yeah, to ease his breathing to help him-- him breathing at night, so, yeah, um, which has helped, um.

[00:41:21] Interviewer: Okay. And is there anything else that you want to tell me about his eating that you haven't really talked about?

[00:41:28] Interviewee: Yeah, um, no, I can't-- there's probably something-- probably, there probably is, but I can't think of anything else now. Yeah, Um, there is yeah, I mean, he really likes ice, and he's got this sort of-- no, they're like these orange juice, um, ice lollies and he can eat so many of those. And he always seems to have that craving for ice, icy things, mm-hmm.

[00:41:58] Interviewer: Okay. And so, do you have any-- any questions for me before we finish up?

[00:42:06] Interviewee: Um, not that I can think of, um, I probably will do as soon as I put the phone down.

Appendix 21: Participant 5 transcript

Interview 5 - [Interviewee's English is second language and a little broken]

[00:02:57] Interviewer: Okay, that's great. So, first question is, um, who else is in your household?

[00:03:01] Interviewee: Um, it's my daughter and my husband, Eric, uh, she is-- and all three of us.

[00:03:08] Interviewer: Okay, and your daughter is on the autistic spectrum?

[00:03:11] Interviewee: Yes.

[00:03:12] Interviewer: What's her name?

[00:03:15] Interviewee: Eva.

[00:03:17] Interviewer: Eva. And-and can you tell me a bit more about her?

[00:03:19] Interviewee: Um, she is basically she-she has a genetic condition, tuberous sclerosis, which causes her delay with different area, and she has epilepsy. Um, and she's generally delayed, so she started to do different things later than -- the same children, the same age. And she was diagnosed with autistic spectrum probably when she was three, just three, quite early. Um-

[00:03:53] Interviewer: And how old is she now, is she ten?

[00:03:54] Interviewee: She's 11.

[00:03:55] Interviewer: 11?

[00:03:56] Interviewee: 11, just turned 11.

[00:03:58] Interviewer: Okay. And tell me a bit about her eating problems.

[00:04:04] Interviewee: About her eating. Um, she wasn't-- Even from the beginning she wasn't very fond of eating of-- She wasn't-- she doesn't like to try any new things. So whatever she knew, she knows, um, it's safe for her. And she has a very, you know, very uh, strict sense of what she likes, what she doesn't like and what she will eat, what she will don't eat. Um, so this is basic.

[00:04:42] Interviewer: Okay. And what-- So, what are your main concerns about her eating?

[00:04:50] Interviewee: Um, her eating, she, um, there were periods of time when she eats just, you know, selected type of food. And she likes to repeat the food every single day, so, um, she doesn't, she's not a very courageous with trying new things.

Um, and basically she doesn't like to eat any fruits, so we don't eat fruit. She doesn't eat fruit. Um, if she eats vegetables, it has to be green, or carrots, she accepts carrots, but only the raw carrots. So, when she sees carrot in a soup or wherever, cooked carrot, it's not eatable. Um, so my concern is, basically, when she eats over and over that type-type of food, um, it's, you know, it's obviously lack of vitamins or-- The ingredients have to be taken by food to the body, so, I think, you know, it limits the, um, you know, you know, we generally have growing or whatever else she needs to-to-to have from-from the food.

[00:06:17] Interviewer: And has it caused-- do you think it's caused her any medical problems in the past, or is it causing her any health problems?

[00:06:22] Interviewee: Oh yes. So we had a-- You know, she was constipated all the time. But I didn't know it-- You know, obviously, we knew when she was really severe constipated and she cried on the toilet and her bowel was bleeding, you know, we had blood in a-- in a-- in a toilet. Um, so-- and we didn't know is um-- we didn't realise that the constipation is a problem and causing other problems until she had multiple, um, urine infections in one year. And it lasted probably two years and she repeated urine infection when we get to the, uh, to the clinic, urine clinic and they said because of the constipation, basically, she had a urine problem. So we came back to-to, you know, to the eating disorder, which causes something which I didn't think is directly linked to--

[00:07:32] Interviewer: Okay.

[00:07:33] Interviewee: Yeah.

[00:07:35] Interviewer: And has she ever had any problems with growing or anything like that?

[00:07:39] Interviewee: No, she's big, she's big. So, she's not little, she's big, she's tall, she's more than, you know, over average. So this is, you know-- this is, you know-- she is growing and she's big.

[00:07:50] Interviewer: Okay. And how do you-- how does it affect you? Like how does her eating problems affected you? How do you feel about it?

[00:07:59] Interviewee: Uh, the eating problems, we um-- but basically, when we, um, wanna go wherever out, I have to be prepared. So the, um, we have to, you know, she's 11, she's quite big now, but we have to develop the way how we can f-- feed her when we are around. Because we had a, um, I remember a certain period of time she ate only scrambled eggs. And when we wanted to spend the day out, wherever, with friends or in church, even, so I have to find a place where can I go and fry, do the scrambled eggs. Because she would not eat anything else.

But when she was hungry, she didn't like to eat anything else and then, when she was hungry she was unbearable. Her behavior was unbearable. Was frustrated, throwing things, she wasn't happy with anything. Obviously, because she was hungry. But she refused to eat anything else, um, when we were around. So--

[00:09:17] Interviewer: And so, for eating out now, is that still an issue? Going-going out to eat?

[00:09:21] Interviewee: No, no, we, we manage to a-- We managed to introduce different things, like McDonalds or wherever we are about. So, we have to think, you know, what we can do when we go out. What we can find wherever we are, now outside of the house. So, she can eat McDonalds, um, and she-- probably she likes that. The toys, the toys are-are the key, uh, for, for eating something like some chips and even burgers or chicken nuggets, so she can eat those.

And then we wanted to introduce something else and she can eat, um, like fish and chip shops, um, just chicken legs. For the moment she can eat chicken

legs, so we have two options, we can find McDonalds or chicken legs. Wherever, from chicken, um, fish and chips shop, they have, so we can do.

[00:10:26] Interviewer: And how about going away? Do you manage to go away on holidays at all?

[00:10:32] Interviewee: Oh, yes. So yeah, we, uh, we go, so, you know with the holidays is the, like, when she was younger, we've been, for 11 years we've been only once in a hotel and it was nightmare. And I was-- I was completely, you know, exhausted. So the, um-- we can't go on holiday somewhere where it's not self-catering, um, because when she was little she was-- she didn't like to eat anything from the menu, and then she was running around the-the-the restaurant touching the people and, you know, going around so it was, no, she couldn't sit wherever she had to sit, so it was nightmare.

So, we've been only once when she was younger and we never go to holiday. Somewhere to proper holiday, you see? So wherever we're going on holiday, I'm just visiting my mum. And she cooks at home. So it's, um-- Oh, and another thing what she can eat know is Frankfurters. So, if we buy the packet of sausages, you know, with us, so we can feed her somewhere where we are out.

[00:11:54] Interviewer: Right. Okay.

[00:11:56] Interviewee: Oh, the holidays, yeah, good question, really. I didn't realise that. [laughs]

[00:12:02] Interviewer: And, um, and how does your, um, your husband feel about her eating?

[00:12:07] Interviewee: Oh, we adjust, um, to her fussiness, um. No I don't know do we think anything of it.

[00:12:22] Interviewer: [laughs] Got used to it.

[00:12:25] Interviewee: He adjust, you know, we've struggled wi-- to feed her with different things, but it was a like-- we gave up - somewhere.

[00:12:33] Interviewer: And what happens when you try to give her new things?

[00:12:36] Interviewee: New things?

[00:12:37] Interviewer: Yeah, what happens?

[00:12:38] Interviewee: Um, it's interesting, you know, she doesn't like to eat anything new, so basically. I try to, when I'm eating something, you know, what I like, I try to give her a taste, but she's not interested, she is just turning around. Not interesting or she can say, "yuck" and, you know, go to do whatever she wants to do. Um, new things... But sometimes-- sometimes, like surprisingly, she can eat food-- Like recently we visited our friends and they had a mushroom soup with a whole mushrooms inside. Not a whole but sliced.

[00:13:21] Interviewer: Yeah.

[00:13:22] Interviewee: And I was 100% positive she will not eat it. She will refuse because she never-- you know, I never made this soup and never had an idea she would like to eat mushroom soup, but surprisingly-- probably she saw a-- no, she listened about mushroom in a film about mushrooms or whoever saw the mushroom in a film, and she just found it the-- and she wanted to have a mushroom. Though she ate all the mushrooms from the soup my friends had at home.

[00:13:57] Interviewer: Uh huh.

[00:13:59] Interviewee: And from-from this incident, you know, two weeks ago, she wanted to have mushrooms every day.

[00:14:05] Interviewer: Oh?

[00:14:07] Interviewee: So, we are in the mushroom season at the moment.

[00:14:09] Interviewer: Fantastic.

[00:14:10] Interviewee: Yes, that so- so I can cook, I can do the mushroom soup and the scrambled eggs with mushrooms, and we can do this every day and we are doing every single day just over and over at the moment. So,

basically she doesn't like to try anything new, but if she does, I mean-- you know, sometimes, you know. But it's very rarely, it's not happening every week or every even month. When she tries something and she likes it so we can introduce to the-- um, to her menus.

[00:14:48] Interviewer: And if-- so that was-- that was an example where she just spontaneously started eating something new. Um--

[00:14:54] Interviewee: Yes.

[00:14:55] Interviewer: When-- For other foods, is it something that you have like a process to try and get her to try something new or do you just wait for it to happen spontaneously?

[00:15:08] Interviewee: I just w-- wait for when it's happens. Yeah, because it's-- For me at home it was waste of food basically. If I try to prepare something which she will not eat is, uh, you know, I have to be prepared to-to consume the food I prepare, um, preparing. So it's just no, no I-- I don't have any plan-- a plan to introduce a new food.

[00:15:38] Interviewer: And how-how is her eating at school? Is there any different?

[00:15:43] Interviewee: Uh, in the school, um, she eats everyday.. fish fingers. Whatever is served, you know, I know it's a lovely menu, but I know every day they have, uh, three fish fingers for her, and she eats it every day, and they have-- She-she likes salad, so when there is a salad buffet, so she can serve herself like cucumber, um, or the green salad, whatever is green, or raw carrot if they have, or coleslaw salad. So, she can eat those, she can eat rice, if it's rice or chips.

[00:16:26] Interviewer: okay.

[00:16:27] Interviewee: But no like chew or whatever else is served or-- and any other kind of, uh, food, it's no. But every day she has three fish fingers.

[00:16:42] Interviewer: And do they do any work with her at school on trying new foods? Does she do cooking or anything like that?

[00:16:48] Interviewee: Yes, she does and she enjoys cooking. It's funny enough-- yes she enjoys, she enjoys to make-- making different things, and she might try what she's cooking, um, but you know-- Yeah, she enjoys the process of cooking, which is good.

[00:17:14] Interviewer: Okay. Um, you didn't get a chance to send me any photos, did you, of her eating?

[00:17:19] Interviewee: No, no I just, you know, I didn't manage.

[00:17:22] Interviewer: No that's fine. I mean if you-- if you find some photos afterwards, um, over the next couple of weeks and you want to send them through then that's great.

[00:17:30] Interviewee: I will, I will.

[00:17:33] Interviewer: And just with them, if you put a caption with them about what you're trying to tell me about her eating then, um--

[00:17:38] Interviewee: All right.

[00:17:39] Interviewer: --then that's really useful. It's-- it was optional, so it doesn't matter if not-- Um, but can you tell me if I was-- if I was sort of an outsider watching a meal time with her, what would it look like? Does she sit down at a table, does she enjoy eating?

[00:17:53] Interviewee: Oh, basically no, we, uh-- she has her own table, and usually when is the meal time wherever we are, her meal time is whenever she dictates her mealtime, when she is hungry, because when everybody is sitting and eating and she's not hungry, she just, you know, ignore it. Um, her mealtime is-- she has her own the table, and we can sit in one table and she can sit next to us with her food. So, she is interested with her food presented in a certain way, she doesn't like to mix, um, food. So if she eats like, um-- she eats the salmon-- She likes, um um uh, salmon, um, not-not cooked but the smoked one cut in pieces. Oh, it has to be like laid down on a plate, and she will eat with her finger or a fork. It's um-- we can't mix it with anything else.

[00:19:07] Interviewer: Yeah.

[00:19:08] Interviewee: ..it has to be single food, um, single time. When she has the cucumber, she has cucumber, when she has carrots, carrot. Um, if you come-- though it might be strange. [laughs] It might be quite, quite, quite strange. It's not like, um, social time eating, I think with social time, when you're sitting together and have a nice time, no. she just has a food to eat, she will eat what she likes and usually-- Because I learned, I know what she likes, I give her only the things she likes and she will eat.

[00:19:50] Interviewer: And does she, um, I can't remember-- does she have, can she speak? Does she have, um-- does she ask you what she wants? Or how does she let you know what she--?

[00:19:59] Interviewee: Oh, she-she speaks. Without she-- if-- she doesn't have a, you know, very wide vocabulary but she has agenda for everything. When she wakes up, I ask her "What, um, would you like to eat, um, breakfast?" and I know the answer because every day is like, you know, it's the same basically.

[00:20:20] Interviewer: Okay.

[00:20:21] Interviewee: So at the moment, uh-- and it's-- it varies from time to time, changes, but in the morning, uh, she likes to eat uh like-- At the moment because it's the mushroom time, so it has to be scrambled eggs with mushrooms. So, egg with mushrooms and two frankfurters, and mint tea, and water. So there is four components for the breakfast and it has to be everything presented four things. And in a certain, um, way-- certain, uh you know, first has to be eggs, then frankfurter then tea and water. [laughs]

[00:21:05] Interviewer: Okay.

[00:21:07] Interviewee: So it's a certain, you know--

[00:21:08] Interviewer: Sequence, yeah.

[00:21:08] Interviewee: Yes. And, uh, before we had a mushroom, uh, time it was, uh, it was sandwich. Sandwich that has to be buttered and, um, cheese. Just-just sandwich, toast with cheese. Butter and cheese. Sometimes a

cucumber. So this is, you know, we quite managed to build up the-- You know, she can eat sandwiches at the moment, which is achievement ... because otherwise before she, uh, prefers to eat like, um, butter with spoon, uh toast separately, um, cheese separately, and cucumber separately. But now we have-- we can combine it into a sandwich, which might be an over a-- you know nothing unusual for another child but for us it is achievement: she can eat sandwiches!

[00:22:11] Interviewer: And how did you move from having it separately to having it together?

[00:22:15] Interviewee: Um, we managed to-- Yeah we-- Um, we managed to do this like, um, some, um, the slice of toast with butter, and uh-- you know, gradually, gradually, but we managed to do this, um-- Just to cut in small pieces and I gave her, you know, small pieces of the sandwich with the fork or I gave her every time I had two forks and I just, um, pierced the-the-the-- tiny piece of that sandwich on the fork and I gave her a fork so she can manage to eat, you know, freq-- you know, whole sandwich together.

[00:23:05] Interviewer: Mm hmm.

[00:23:07] Interviewee: Um gradually, probably. And as well at the moment, um, she will prefer if she, uh -- when I'm not supervising her, she would probably-- and I will not cut them and not supervise, she will eat, um, everything separately. She will take, from the sandwich, she will take cucumber first, cheese and then she might lick some butter and-and leave the-the bread out.

[00:23:41] Interviewer: Okay, okay. So you're making s-small changes but there are changes happening.

[00:23:48] Interviewee: Yes, yes. There are, there are, there are. Yes, we didn't give up completely. [laughs]

[00:23:53] Interviewer: No, no. That's great.

[00:23:55] Interviewee: We tried to do, um you know, some introduce something new.

[00:23:57] Interviewer: Mm hmm.

[00:23:58] Interviewee: Um but it's not everyday. Uh, I'm not as ambitious to-to encourage new everyday, no.

[00:24:06] Interviewer: [laughs] Fair enough. And so, in the past, what sort of professional help have you had with um her eating, if any? Or-or non professional, I don't know. Have you had help from other parents or, um, have you found advice on the internet or have you had-- have you-- did you see people in the past that gave you some advice?

[00:24:29] Interviewee : I don't remember, really. Um I don't remember, really, how it was, um--

[00:24:37] Interviewer: When she was-- when she young, so when she was sort of two, three, four years old, did she have eating problems then?

[00:24:45] Interviewee: Uh, she was fussy. I don't think we call it eating problems.

[00:24:50] Interviewer: Uh huh.

[00:24:51] Interviewee: They call it, "She was fussy."

[00:24:53] Interviewer: So you just--

[00:24:53] Interviewee: And "Wouldn't like to eat something" So, you know, probably the same age, you know. Different children have the same--

[00:24:58] Interviewer: Yeah.

[00:24:59] Interviewee: -um time, they didn't like to eat something what they used to eat when they were babies.

[00:25:05] Interviewer: Mm hmm.

[00:25:05] Interviewee: So, we didn't-- we didn't-- we didn't really think of it as a problem.

[00:25:11] Interviewer: Yeah.

[00:25:12] Interviewee: It was just, uh, you know, just the stage of, um, development, um, that the child is fussy.

[00:25:17] Interviewer: Sure.

[00:25:18] Interviewee: But from the fussiness, it, uh, it starts to be regimented to one type of food.

[00:25:24] Interviewer: Mm hmm.

[00:25:25] Interviewee: And then, when it was one type of food-- Um, so I-I tried to add, you know, just to extend the-the food she tolerates. So, it was probably experiments made at home with whatever she-she would like to eat and-and try to eat or feed her. Or, you know, sometimes she, you know, it was, um, like bribing her.

[00:25:51] Interviewer: Mm hmm.

[00:25:52] Interviewee: Which, uh you know, which works, in our case.

[00:25:55] Interviewer: Mm hmm.

[00:25:57] Interviewee: If she wanted to have a reward, she has to finish something which was healthy. And like soup or-or the dinner she has to finish it before she will have a reward.

[00:26:08] Interviewer: Okay. And what sort of rewards did you use?

[00:26:11] Interviewee: Uh chocolate.

[00:26:13] Interviewer: Ah okay, so food rewards, yeah.

[00:26:15] Interviewee: Food rewards or the, um, uh, the YouTube, film.

[00:26:21] Interviewer: Uh huh.

[00:26:22] Interviewee: Um films, always, you know, the films are-are very good. And as well, she used to when eating, sometimes she has something playing at the same time. We don't have a television switched on, but she has a like, uh, small tablet and her favorite, you know, um, tales at the moment.

[00:26:48] Interviewer: Mm hmm. Okay. So, that's-- is that a normal thing to have it on whilst she's eating

[00:26:51] Interviewee: Yeah, yeah. With regret.

[00:26:53] Interviewer: Okay, yep. And-and so, you've seen-- you've seen me recently as a dietitian.

[00:26:58] Interviewee: Yes.

[00:26:59] Interviewer: Was that-- Did you ask for that? Or was it the doctor asked for it?

[00:27:02] Interviewee: Yes, I did ask for it.

[00:27:04] Interviewer: Okay.

[00:27:04] Interviewee: Because um we-- I didn't know, uh, I can-- Because with her, like, she wants to eat a certain kind of food.

[00:27:13] Interviewer: Mm hmm.

[00:27:14] Interviewee: And I thought it's, um, from my perspective, I thought, "No, it's not enough."

[00:27:21] Interviewer: Mm hmm.

[00:27:22] Interviewee: It doesn't cover the-the, you know, all min-minerals or vitamins.

[00:27:31] Interviewer: Mm hmm.

[00:27:32] Interviewee: And, uh, probably, we have to speak to someone about it. So, it was, uh, it was quite late because it was when she was 10.

[00:27:41] Interviewer: Yeah.

[00:27:42] Interviewee: Ask for the-- for the help.

[00:27:43] Interviewer: And why was it and what do you think, sort of, um, triggered you wanting help then? Was it --was it that her eating had got worse? Or just that, you know, you just sort of suddenly--

[00:27:54] Interviewee: I thought, because she was in a period that she has eaten like 10 eggs a day and she didn't like to eat anything else.

[00:28:03] Interviewer: Mm hmm.

[00:28:04] Interviewee: And one of the doctors in, uh, one, um, one of the consultations, um, I said, you know, she's eating all the time the-the eggs and he said, "You know, it's fine. You don't have to worry about it. But when the puberty comes, you have to think of it."

[00:28:23] Interviewer: Mm hmm.

[00:28:23] Interviewee: So because it was a time she has-- she has eaten only eggs, and the puberty, you know, will come very soon. And I thought, "No. It's, um you know, I have to have some help." Because if it lasts like this, I-I have to change something, but how or where to go, um, I didn't have any idea. But, you know, surprisingly, she stopped eating, uh, she-- by herself, she just reduced her, um, her eggs. So it was-- we had eggs only for years.

[00:29:03] Interviewer: Mm hmm.

[00:29:05] Interviewee: Uh and then suddenly she just-- it was the frankfurters, the-the-the chicken sausages period. And she wanted to eat sausage-sausages, um, breakfast, lunch, and dinner all the time. So we, you know, somehow she managed to change.

[00:29:26] Interviewer: Okay. And before-- So previously, have you-- have you seen a dietitian before? Or is that the first time?

[00:29:32] Interviewee: No.

[00:29:32] Interviewer: First time. Have you-- Um, at school, did she get any help with her eating from people like occupational therapists or anyone like that?

[00:29:41] Interviewee: I didn't speak to anyone. But, it might be somewhere covered in the school because her school is very, you know, um, is quite good.

[00:29:50] Interviewer: Which one does she go to?

[00:29:52] Interviewee: Um its a special needs school - I know there are people working, um, in the occupational therapy, as well.

[00:30:01] Interviewer: Yeah. Which school does she go to?

[00:30:02] Interviewee: Uh Watergate.

[00:30:04] Interviewer: Watergate, okay, yeah. And, um so, in an ideal world, what professional help would you have like to have had in the past? Or would you like to have going forward? What-what sort of things do you think might have helped? And when would you have like to have had them?

[00:30:24] Interviewee: Hmm, it's a good-- I, uh, before-- I don't know how-how it should be, you know. I have no idea. I know that the time when I have a help was the conversation I had with you. The-the-the main thing was, I just realised the constipation is having, um-- you know, it causes the problem. And I did, you know, nobody before explained me, uh, the importance of the consistency of the poo [laughs] for the overall health. And I think it was the-- You know, I had a conversation about food every time when I met paediatrician. And so-- and we are meeting quite frequently, so every half a year. The conversation we have-- well once a year. So, always, I have a-- I had a conv-- you know, conversation but they didn't think-- No, I managed. So, I didn't ask for the help before because I thought I managed.

[00:31:34] Interviewer: Mm hmm.

[00:31:35] Interviewee: Um, so it's difficult for me to say, "Probably, each child is different." Maybe sooner, when she was constipated and she had a very frequent urine infection. Maybe it would be like three years ago or four years ago, we might manage to, um, to have less problems.

[00:31:57] Interviewer: Uh huh.

[00:32:00] Interviewee: Um.

[00:32:01] Interviewer: And when she was first diagnosed with autism then, did you go to things like the EarlyBird groups? Did you-- did you attend any of that?

[00:32:10] Interviewee: I probably had.

[00:32:15] Interviewer: They're like the, um, they're run by, um--

[00:32:16] Interviewee: The Kaleidoscope.

[00:32:17] Interviewer: Yeah. They're normally, like, teaching you a bit about what autism is and sometimes they cover a bit about eating problems.

[00:32:25] Interviewee: I attend everything, so I probably had it. But it was quite, you know, long ago.

[00:32:31] Interviewer: Okay. And you don't really-- you don't remember?

[00:32:34] Interviewee: Saying, "Early Bird" and it rings a bell.

[00:32:37] Interviewer: Okay, yeah. And, um, so I suppose, with her-- She's got-- She sounds like she's got a few different sort of problems with, you know, communication and, um, and her other epilepsy and her other medical problems. So with her eating, how would you rate it as sort of your.. a priority for you guys? Do you think it's sort of something that is, um, lower down on your priorities or--?

[00:33:05] Interviewee: It was. Definitely, it was.

[00:33:06] Interviewer: Yeah. Okay.

[00:33:08] Interviewee: Yeah. I think we had a, you know, bigger problems and we didn't concentrate as much on eating of, um, as on other things.

[00:33:16] Interviewer: Mm hmm. Okay. And-and sort of now with, um, you know, you've started to be a bit more, um-- where the doctors have raised concerns about her eating going forward and into puberty and things like that. So, what sort of help do you think might be useful to you as a parent, if any, or would you like the help to be focused on working directly with Eva? Or do you feel that you sort of--?

[00:33:46] Interviewee: I-- I think, you know, um, you know, it was the help I had, you know, with the meeting with the paedia-- with the dietitian and me to prepare just a week, like, to-to write down what she eats exactly for a week, it

was very good. Um, maybe somewhere the support group or the contact or the nurse or dietitian nurse of, I don't know, a-- uh, something like-- this exists. Um, just to come over if-if we have a problem or to have a.. any-any questions.

[00:34:32] Interviewer: Mm hmm. So, all this--

[00:34:33] Interviewee: I like to-- it's very well-- You know, when she was little and it was like the, breastfeeding café, a place like this, and we had a very good, um, support over there because all the-- you know, can come in you, you have two professionals, you know-- once a week if you ever have a, you know, whatever concerns you can pop in and just to-to ask whatever is your concern.

So, it's like I'm going-- I knew I had an access to it, uh, whenever I have a problem or-- not having problem, just to have a chat. Uh, so I think it's-it's quite good to have sort of help, not regimented to one child. It's like one-to-one support because it's quite, um, expensive, but something which is, um, available to all parents in need.

[00:35:34] Interviewer: So, like a drop in, that sort of-- that's quite convenient.

[00:35:36] Interviewee: Drop in, yes. Drop in. Yes, it would be-- It would be probably helpful.

[00:35:43] Interviewer: Yeah. What do you think-- what do you think the benefits of it being like a drop in is? What-- Did you find it was sort of-- that you had instant access or was it a bit less threatening or--?

[00:35:55] Interviewee: I, uh, the-the drop in?

[00:35:56] Interviewer: Yeah.

[00:35:58] Interviewee: I think, you know, what what was good. It was, like, organised and prepared. Uh, it was more-more parents as well. I can hear other parents' views and other parents, um, as well, you know, what they have at home, their experience is. So, I think it was-- as well moderated by-by professionals so it doesn't go off-train somewhere, you know? Um--

[00:36:37] Interviewer: Mm hmm. we-'ve we-we've thought about having groups for parents. I suppose it wouldn't be so much a drop in, but it might be like three sessions and it would be parents of children with autism, with feeding problems and they could come to a group where we sort of talked about different strategies and the parents could share things that worked. Would that be something that you think might be useful?

[00:36:59] Interviewee: Very useful.

[00:37:00] Interviewer: Yeah. Okay.

[00:37:01] Interviewee: Very useful. Because, you know, I think the lack with me I didn't have an idea of a strategy I could have. Uh, so, I just tried what I-- what I had in my common sense, um, and, you know, so-so I think, yeah, very good idea.

[00:37:22] Interviewer: And how about-- So, I mean, with things in the NHS aren't so great financially, and so, how about things like online help? If there was sort of an online forum just for, like, Lewisham parents or something like that, is that something that you that you would-- you might access?

[00:37:40] Interviewee: For me?

[00:37:41] Interviewer: Yeah.

[00:37:42] Interviewee: Well, I'm too old for this.

[00:37:44] Interviewer: No?

[00:37:44] Interviewee: For this, uh, yeah, yeah. Probably with the online-- I'm not looking to online help.

[00:37:50] Interviewer: Okay.

[00:37:50] Interviewee: I'm not this-- maybe the-the-the parents 30 or 20 plus they will be happy with online groups. I probably, I prefer just to, um--

[00:38:02] Interviewer: Face-to-face.

[00:38:03] Interviewee: Yes. And so, what-what-what I think, because with eating disorders I think that the parents have to be taught. And, um, especially with the food probably you have to be taught how to prepare something or how to prevent something because sometimes it does-- it does matter. Absolutely, it does matter with, uh, with my child. So, it might be as well, um at home, like a exercise.

[00:38:38] Interviewer: Yeah. And how about if we-- how about if we have something like a sort of self help menu, you know like a sort of a paper-based resource that you could work through with yourself and your child and then get a bit of support with, would that be something that might be useful or--?

[00:38:54] Interviewee: I think yes. Yes, yes. because, it will be like a book and so the child can be involved. Yes, it's always, um, yes, my child was always, you know, very-- she likes to go for books.

[00:39:10] Interviewer: Okay. Yeah. And um, so a slightly different question. Have you, um, have you ever thought about trying-- I mean to-- Hold on, I'm sorry. First question, d-does she take any supplements, any vitamins or minerals?

[00:39:26] Interviewee: No. I didn't give her.. too much. Or never. I didn't give her... When she was very little I gave her like, uh, fish oil or whatever, the drops, Omega-Omega 3 when she was little. And then later I just, uh, felt it's not necessary to give her any supplements and nobody was th-- professional help, nobody suggested it, I have to give her anything else, any supplements, so I didn't. Um--

[00:40:02] Interviewer: And do you read, I mean, have you read anything about sort of special diets for autism, things like-- There are things out there like gluten-free or milk- free or-- there's lots of different-- if you get-- particularly if you search online or ask other parents. There are lots of different people that will say, "Try these supplements" or "Try this diet." Has that-- is that something you've ever tried or thought about?

[00:40:27] Interviewer: No. No, I never tried it. I knew-- I-I know that, um you know, a lot-- I have a friend who put her son on a gluten-free diet and there was very good results. She had a good result with gluten-free.

Um, with me, because Sasha was very fussy and didn't like to eat a lot, um, so I thought for me it was a big gain if she eats something so I d-- and I thought if I will restrict myself to any certain diet I will limit myself when I'm happy when she starts to eat anything, you know. So, I didn't think of it. I just felt it will, like, limit my choices. I probably am wrong.

[00:41:24] Interviewee: No, not nece-- I mean, I'm not saying that's it something that you should try, I'm just interested in whether it's something you thought about. Um, and so, is there anything else that you want to tell me about, um, about your child's eating problems or how it affects you or anything else you haven't thought about?

[00:41:44] Interviewer: Mm I don't know. I think it's good to have a, you know, the professional help. I think this is-this is important and just touch it, um, maybe before it's too late. Just to give, uh, the knowledge for-for the parents, I think it would-- it might be good.

[00:42:10] Interviewer: And actually, I'm interested because you're saying that-- So, so, Every year you see the paediatrician?

[00:42:14] Interviewee: Yes.

[00:42:15] Interviewer: And does-- did the paediatrician give you any advice or any sort of reassurance about her eating or--?

[00:42:22] Interviewee: Uh, yes. I think, you know, because, you know, we've been always asked, you know, what-- She does eat vegetables, does eat, uh, egg and salmon and she does eat bread. It's very-- You know, it seems to be not too, um, bad diet. Overall it wasn't too bad and I've been to the different parent groups as well. I don't remember it was in-- Uh, how are they called? Um, when my child was-was younger, it was like a nurses caring for the-for the disabled children.

[00:43:12] Interviewer: Um.

[00:43:14] Interviewee: I can't remember the name at the moment, but they must have been at Kaleidoscope.

[00:43:16] Interviewer: Yeah.

[00:43:19] Interviewee: And-and we've been to the, um, to the groups and I-I-I know it was very, um, good support for me.

[00:43:29] Interviewer: Mm hmm.

[00:43:30] Interviewee: With, um, early stages

[00:43:34] Interviewer: Mm hmm. Okay.

[00:43:38] Interviewee: So, I think with the-- with the eating it wasn't as much, you know, um, restricted because I know that the another-- and everybody said, "Oh, you know, it's not too bad because other children, they will eat only, you know, one type of crackers only."

[00:43:54] Interviewer: Yes, so compared to other children with autism, yeah.

[00:43:56] Interviewee: Yeah. Compared to other children, so. Compared to other children, we were, uh, we were in a good, you know, good, uh, stage or wherever. I was assured so it's not too bad. It's quite-- it's quite good.

[00:44:15] Interviewer: Yeah.

[00:44:16] Interviewee: So, it was, um, you know, in comparisement [sic] to-to other children.

[00:44:20] Interviewer: Okay.

[00:44:21] Interviewee: But I never had a-- you know.

[00:44:23] Interviewer: Fair enough fair enough. [laughs]

[00:44:24] Interviewee: I never think, you know, it's too wrong [laughs].

[00:44:27] Interviewer: Okay. And I'm glad to hear that, you know, when you came to see us that hearing a bit about things like constipation helped because I'm-- it's useful, um--

[00:44:37] Interviewee: Yes, it is. It is. It is very useful. I didn't realise. It's um-- Talking about poo is, um--

[00:44:44] Interviewer: Mm hmm. Yeah, okay, so, um, thank you, um, thank you for all of your answers. It's been very useful. It's um-- I think it will be-- It'll really add to, um, our research.

Appendix 22: Participant 6 transcript

00:02:27] Interviewer: Okay. So, you have -- tell me about who you've got in your family.

[00:02:34] Fiona: Myself, my husband and our daughter, Fay.

[00:02:38] Interviewer: Okay and how old is Fay?

[00:02:40] Fiona: 13.

[00:02:41] Interviewer: 13, fabulous and she have ASD, does she?

[00:02:44] Fiona: Yes.

[00:02:46] Interviewer: And how does that? Tell me a bit how that affects her?

[00:02:50] Fiona: She was diagnosed very young and from quite extreme repetitive behaviour. She's about 2 1/2 when she was diagnosed. When she's 2 1/2 age, she was hypertonic-

[00:03:05] Interviewer: Okay.

[00:03:06] Fiona: -she was born floppy. She had lots of physio when she was first born. She couldn't latch on, she was tube fed and then she had terrible hypersensitivities where food is concerned. Show her a bottle and she cried when she cried and back away she'd laugh, smile. It turned out that she had pitting tonsils. Then she had tonsils, adenoids and grommits done at 22 months and.[....]

[00:03:43] Interviewer [crosstalk]: So quite a tricky start..

[00:03:43] Fiona: ..because she wasn't developing. Uh, she was tube fed up to about 4?

[00:03:53] Interviewer: Okay, wow, yeah.

[00:03:54] Interviewee: Very delayed in everything. So, um global development delay, um milestones didn't really affect her at all, she was so delayed. Non-verbal, her first words were Makaton, which is sign. Um, Very alien like - she'd just sit and watch, didn't want to participate in anything.

Um, Went to a special needs nursery called, "xxxx". Fantastic, absolutely amazing. Um she had spatial paramater problems and still had the feeding problems with sensitivities. Would freak out when any food touched her fingers, touched her face and couldn't bear anything on her own clothes, still can't. If you get food on her clothes at any point, even the slightest blob of anything, she has to change.

Um... Still can't wash herself properly, she can dress. I have a shower with her just to supervise, now - we've got to a point where she can do it. She's confident as long as there's somebody in the shower with her. We are getting there slowly.

She attends the special school. She can now read. She can write.

[00:05:34] Interviewer: Fabulous.

[00:05:36] Fiona: And I think she is awesome. I learn from her every day. She's wired up differently, obviously, but incredible. She has the most amazing memory. She wears glasses. She has permanent glue-ear, so you have to get her attention to to speak to her. So, she sort of partially lip reads I think, and can't hear what is going on if she hasn't have her glasses on,... um but she's great. She's the happiest child, I've ever met.

[00:06:11] Interviewer: Oh, that's lovely to hear.

[00:06:13] Fiona: Yes. She's brilliant and I'm proud of her progress.

[00:06:18] Interviewer: So, she's 13 now you said.

[00:06:20] Fiona: Sorry?

[00:06:21] Interviewer: She's 13 did you said?

[00:06:22] Fiona: 13 yes she'll turn 13 in November.

[00:06:25] Interviewer: Which school does she go to?

[00:06:26] Fiona: [unintelligible 00:06:28]

[00:06:27] Interviewer: Okay and did she get on well there?

[00:06:29] Fiona: Lovely.

[00:06:30] Interviewer: Oh, that is good.

[00:06:31] Fiona: She started at, oh God whats it called I cannot remember. It was a little school at the end of our road. I remember, she lasted three months. There was a play telephone box that she wouldn't come out of.

[00:06:46] Interviewer: Okay.

[00:06:46] Fiona: The whole time she was there she just couldn't cope. It was really stressful for her.

[00:06:52] Interviewer: Oh bless.

[00:06:54] Fiona: So we took her out of there.. and … because of her special needs diagnosis she was attending a lot of walk-in sessions on a Friday morning and then they offered her a place when we took her out of the school at the end of the road, which is great. So, she was there and then started at xxxx school um from reception.

[00:07:29] Interviewer: Okay, and tell me a bit about how, how, what her eating is like.

[00:07:34] Fiona: Um, now it's not too bad, we know she can't eat unless there's a drink beside her um and she still gags a lot um the food size has to be just right.

Um when she was tiny, to help with her hypersensitivities, I put massive plastic sheetin' on the floor in the lounge, put a great big bowl on the floor, full of jelly, an' I sat 'er in it and she thrashed around and …hated it for about a minute and then, wow! …It took a while but.. she loved it and she was then… it took some time.

Um I remember it was one of the things… so.. er.. we used to… everything was.. um.. because she was tube fed for so long um four out of six.. no.. two out of six feeds used to come up. She was bolus fed and with the hypotonia she had trouble with the muscle sphincters, the stomach sphincter and the

oesophagus so um she she had terrible reflux um she had to sit a certain way to receive the bolus feeds and then we started to introduce.. we had a sippy cup.

We try and ..uh.. introduce solids rather than the bolus, so it was a squeezy cup, very flexible cup that we'd give her a little bit now and then and then introduced soft foods and then the jelly and then oats and bits of vegetables and fruit and... So, over time it built up food that she would touch, and then over time we would cut out the bolus feed..we.. we made a decision with Lewisham Hospital to take it out... an' she lost an awful lot of weight really quickly and then we were at the point where we were gonna put it back in again and we said no… just, you know, stick with it and we did and she really turned it around. And um, She was then eating independently, and um, I think, the first time she sucked on a straw, how old was she?.. she was about seven.

[00:10:21] Interviewer: Wow, okay.

[00:10:23] Fiona: And that was amazing, because we were on holiday, sitting in a cafe and uh, they brought instead of her normal pour sippy cup. They brought a glass with a straw in it and she just picked it up as if she'd always done it. Oh, and we were amazed! So, her milestones have been humongous when they've happened. She crawled for a long time, she didn't walk for a long time, she just crawled constantly and I worried about dyspraxia. She has ADHD tendencies, dyspraxia, global development delay, he has a chromosome disorder, which is very rare, there is only one other case that we found online of a young man in America. He's in his thirties now, and he's quite severely… disabled physically and mentally. She's quite the exception, she's amazing.

She had a barium swallow when she was little, because they- we didn't know why there was so much reflux. Her hospital file's about a foot thick. So, now feeding-wise is much, much better now. We all know, you know, that she has to have a drink beside her when she eats now. Sometimes, textures are an issue, still. And now that she's gone into secondary school at Brent Knoll she's doing - um- what do they call it? Not Home Economics anymore. Food Tech.

[00:12:24] Interviewer: Okay, yes.

[00:12:26] Fiona: She's learning- because she has- she's got no interest at home-

[00:12:31] Interviewer: ***[DOORBELL RINGS]*** Oh, excuse me. Sorry about that, that might be the postman let me just grab that…..

…

[00:13:11] Interviewer: Sorry. Sorry about that Fiona, you were saying that she's- she's having Food Tech at Brent Knoll.

[00:13:14] Fiona: Yes, Food Tech at school and so learning about food and cooking it. She's doing different things, so that's been a real bonus.

[00:13:26] Interviewer: She enjoys it?

[00:13:27] Fiona: Yes, but she won't- she won't help me in the kitchen at home. That's probably me being impatient, but we do- I do try and do sessions with her. You know, she's noise sensitive, light sensitive, food sensitive. So she doesn't like the mixer going….

Oh sorry, hold on a second, I've got an engineer here. So hold on a second. [silence]

[00:13:57] Interviewer: No problem.

….

[00:16:15] Fiona: Hi, Zoe, sorry, I've got a washing machine engineer here.

[00:16:20] Interviewer: Okay, is that right? Can you carry on talking?

[00:16:23] Fiona: Yes, yes, just awful time trying to fix the machine.

[00:16:27] Interviewer: Oh, nightmare. You need your machine.

[00:16:32] Fiona: It's been a month now. The laundrette has been a regular visiting place. So, yes where were we?

[00:16:43] Interviewer: You were saying that Food Tech she enjoys, but at home, you try to do some things with her as well.

[00:16:51] Fiona: Yes, we've,.. I've tried to get her interested in just starting off with Fairy cakes, that kind of thing. But when the mixer starts up, she's gone like a shot. But, I am getting her to spoon the mix into um, the cases, and she's enjoying licking the spoon now, so…

Meal times she likes things to be the same meals and I'm trying to vary what she's eating, and Food Tech is certainly helping, because she's cooking different meals and she's done a stir fry this week with green peppers. They did that on Monday, and she's eaten some of it! I can't believe it, wonderful! Onions and green peppers in this stir fry, and she's eating it, it's fantastic! So, if she's cooking it, she'll eat it.

[00:17:54] Interviewer: That's great. So she won't-

[00:17:55] Fiona: It's brilliant.

[00:17:56] Interviewer: -she won't normally eat those foods?

[00:17:58] Fiona: No. She wouldn't touch them, she'd pick them out.

[00:18:02] Interviewer: What's her- what's her normal diet like? What does she like eating?

[00:18:07] Fiona: She has packed lunch, she likes to eat the school dinners. For breakfast, maybe a bowl of cereal, a banana. Oh, hold on a second ***….[talks to workman]***

[00:18:22] Interviewer: No problem.

[00:18:34] Fiona: Sorry, where were- yes, breakfast would be a bowl of cereal or porridge. If it's porridge, there's a glass of milk on the side. She likes the same cereal, Rice Krispies. Um, Corn Flakes, she won't eat, so she's got- she's picky with her cereal and then she's- she doesn't eat during the morning. She doesn't try and have a snack or- she doesn't go for elevenses or anything like that. Um, she has to be told, reminded, to drink. Always forgets to drink.

She has- it's difficult for her to understand hot and cold. When she's either boiling hot or she's freezing cold. When she was small, she didn't- didn't

regulate her temperatures very- very well. So, um, she would always be freezing cold or boiling hot and I think then it's, you know, the constant reminder of drink- you've got to keep drinking. When you're hot, keep drinking. It's always a reminder, with something to drink.

[00:19:59] Interviewer: And with eating, does she- does she recognise hunger?

[00:20:01] Fiona: I don't know. We didn't for a long time because she was tube-fed.

[00:20:06] Interviewer: Okay, yeah.

[00:20:07] Fiona: She didn't know-- didn't understand the feeling of hungry until the tube came out. And it was then that she started understanding hungry and started feeling hungry. I think it was an-- it was an unusual feeling for her. Her tummy would rumble and she-- she'd be upset because she thought something was wrong.

[00:20:27] Interviewer: Mm-hmm.

[00:20:28] Fiona: And then, you know, in time she learned that it's actually-- well that's your body telling you that you're hungry. So that-- that took a while for her to understand but we've-- we've got there.

[00:20:40] Interviewer: And you said that she's still a bit funny about textures. What do you mean-

[00:20:44] Fiona: Yeah, yeah-

[00:20:44] Interviewer: -about that?

[00:20:44] Fiona: -textures, uhmm. That's why I was surprised about the peppers because the texture-

[00:20:49] Interviewer: Yeah.

[00:20:49] Fiona: -of the pepper.

[00:20:51] Interviewer: What textures does she prefer then?

[00:20:54] Fiona: Uhhhh. Pasta and sauce or pasta and butter.

[00:20:59] Interviewer: Uhuh.

[00:21:00] Fiona: Or something slippery rather than-- than sticky.

[00:21:04] Interviewer: Uh-hmm.

[00:21:04] Fiona: Ummm. The-- the first time she ate a sausage with spaghetti, with the sausage in her hand was amazing. She was-

[00:21:14] Interviewer: Uh-hmm.

[00:21:14] Fiona: -little. And she bit the top off the sausage and she, uh, absolutely loved it and-- umm, but hated the -- residue on her fingers. So that-- that took some time for her to get used to-- diff-- diff-- you know, different textures that's okay, you know, enjoyable to eat but then, you know, you've to think that if it's finger food, which is all she would do for a while, ummm, it was-- we struggled teaching her the knife and fork.

[00:21:42] Interviewer: Uh-hmm.

[00:21:43] Fiona: Uhhhhmm. Uh, what other textures? Uhhhhmm. Broccoli is okay now, it never used to be so-- vegetables, different textured vegetables were, um, were hard for a while. Ummm. She loves dairy products-

[00:22:04] Interviewer: Mm-hmm.

[00:22:05] Fiona: -her yogurt.

[00:22:07] Interviewer: Is she fussy about the temperature of food?

[00:22:12] Fiona: Uhhmm. She doesn't like anything too hot.

[00:22:16] Interviewer: Mm-hmmm.

[00:22:17] Fiona: Uhm, she prefers-- she prefers it to be cold rather than-- than-- than hot. If-- if-- if there's steam coming off it, she'll wait until the steam is gone, so, uhmm, if she's-- so, it'd have to be cold to, umm, only slightly warm. She wouldn't eat anything hot—hot soup has to be cold.

[00:22:44] Interviewer: And how do you fee-- how do you feel, generally, about her range of food? Do you feel like she gets enough of everything or-?

[00:22:50] Fiona: I think so, yes, I think she's-- she's doing very well now. It's taken a long time, umm, you know, lots of persistence and lots of,"try this, try"-- uhhhmm, bananas, so the-- the-- the thickness and texture of meat she couldn't cope with for a very long time. So, chewing, it wa-- the food would sit in between her-- the bottom front teeth and her lip.

[00:23:16] Interviewer: Uh-hmm.

[00:23:17] Fiona: It became a pouch because she couldn't chew.

[00:23:21] Interviewer: Mmkay.

[00:23:21] Fiona: Uhhmmm-

[00:23:22] Interviewer: And she couldn't-

[00:23:23] Fiona: -oh, uhhhh-

[00:23:24] Interviewer: -or she wouldn't chew?

[00:23:24] Fiona: Chi-- chicken is okay if it's freshly cooked.

[00:23:28] Interviewer: Uhuh.

[00:23:28] Fiona: She won't eat chicken the day after.

[00:23:30] Interviewer: Uhuh.

[00:23:31] Fiona: Ummm. The only thing that's a bit too much of an effort to chew on? -- ummmm, white fish is okay because it's soft and it disintegrates in your mouth really quickly. Beef, she won't eat. Lamb, she won't eat.

[00:23:46] Interviewer: Do you think she <u>can't</u> chew? Or do you think she just doesn't chew?

[00:23:50] Fiona: I don't know.

[00:23:51] Interviewer: Uh-hmm.

[00:23:52] Fiona: Uhhhhmm.

[00:23:53] Interviewer: Is there anything she has that she chews? Like sweets or anything like that?

[00:23:59] Fiona: Uhmmm.

[00:24:00] Interviewer: Or bread?

[00:24:03] Fiona: Bread is fine.

[00:24:04] Interviewer: Okay, that take chewing, I suppose.

[00:24:06] Fiona: Can be-- yeah, that can be gloopy-

[00:24:08] Interviewer: Yeah.

[00:24:09] Fiona: - sticky but it has to be a drink.

[00:24:11] Interviewer: Okay. So maybe she's not chewing it a huge amount and--

[00:24:15] Fiona: Yeah, but there always have to be a drink becau-- and-- and she used to, umm, food, liquid used to go into her lungs a lot so she was-- umm, she used to gag an awful lot.

[00:24:27] Interviewer: Uh-hmm. Okay.

[00:24:29] Fiona: Ummm. Can't remember what the term is. What's that? Ummm…. Can't remember.

[00:24:38] Interviewer: [laughs] It's okay.

[00:24:39] Fiona: Ummmm. Yeah, so-- so we-- we have to have a drink there, regardless of-- of what's being eaten. Whether it-- it's, um, umm, if it's soft or hard, it doesn't matter. It's got to be a drink.

[00:24:51] Interviewer: And does she still have reflux? Or is that-?

[00:24:53] Fiona: Yea--yeah.

[00:24:53] Interviewer: She still has reflux, so is she on med-- medication for that?

[00:24:55] Fiona: No, not anymore. She's weaned off.

[00:24:58] Interviewer: And does she go to the toilet okay?

[00:24:59] Fiona: Uhhhh, very loose.

[00:25:01] Interviewer: Uhuh, okay.

[00:25:02] Fiona: Uhm, it's an instant feeling. Uhm,"I'm okay--- no, now I need the toilet."

[00:25:06] Interviewer: Uhuh. Okay.

[00:25:07] Fiona: Uhhhmm. And it's same-- same with her, uh, poo.

[00:25:12] Interviewer: Uh-hmmm. Okay.

[00:25:13] Fiona: But that's very loose, it was always very loose. It-- when she was tiny it was always very loose.

[00:25:19] Interviewer: And what happens-- so, she's-- she's a bit picky around food, would you say?

[00:25:23] Fiona: Yeah.

[00:25:24] Interviewer: And what happens when you try to give her a new food? That you managed--

[00:25:28] Fiona: Uhmm--

[00:25:28] Interviewer: --that she doesn't normally have?

[00:25:30] Fiona: She-- sometimes she'll try it. Sometimes she just says,"no," and that's it.

[00:25:35] Interviewer: Uh-hmm.

[00:25:35] Fiona: Umm, pointless me forcing it because then it's just an aversion to it-- to it completely. So I do, um, as I did when she was little. It's just, you know, try again in a while.

[00:25:48] Interviewer: Mm-hmm. And if, uh-- and what would a mealtime-- typical mealtime at your place look like? Is it, um-- does she enjoy it? Is she sort of sat down for it or-?

[00:25:58] Fiona: Yes, yes, yeah, we sit at the table. I always make sure that the evening meal, we sit at the table and we make it a social thing.

[00:26:05] Interviewer: Mm-hmm.

[00:26:06] Fiona: Uhhhmm. She will eat the-- the-- the same as us.

[00:26:11] Interviewer: Okay. Great.

[00:26:12] Fiona: She-- she will pick out of it what she wants.

[00:26:15] Interviewer: Uhuh.

[00:26:16] Fiona: And she's funny if-- if, uh hmm-- what did we have the other night? I did chicken, um, with, um, a lump of cheese then wrapped in ham cooked in the oven, um, with new potatoes, um, salad. Well, she'll eat the ham first, then the cheese, then she'll pick out the bits of the salad that she likes, so she goes from-- she'll eat all of what she really likes and then down to what I know what she doesn't like. And that's-- that's what left on the plate. And, um, really you've got to have bits of potato so she'll have a bite of potato and she'll have a drink, and then she'll have another bite of potato and then drink pretty quickly. So she knows, you know--she will eat it.

[00:27:02] Interviewer: Mm-hmm.

[00:27:02] Fiona: She was forced into eating it, uh hmmm, but then she'll have a drink to get rid of it really quickly.

[00:27:09] Interviewer: Mm.. okay. What sort of drink does she like having?

[00:27:12] Fiona: Uhhhmmm, she's allowed Diet Coke once a day.

[00:27:17] Interviewer: Mm-hmm.

[00:27:17] Fiona: Uhh, uh, with her evening meal, she'll have a-- a small glass of Diet Coke. Otherwise, it's water, milk. Uhm, rarely, squash. She doesn't like fruit juices, never did. But milk and water, she's very good. Drinking water, sparkling water, plain water.

[00:27:37] Interviewer: Okay. And you said, um, you've taken one photo for me. But I mean, you haven't sent it yet, but umm--

[00:27:42] Fiona: Yes. I've only-- I've only managed to do one.

[00:27:43] Interviewer: Okay.

[00:27:45] Fiona: Umm--

[00:27:45] Interviewer: [crosstalk]

[00:27:46] Fiona: --because she's-- how the plate has got to appear, I-- I was going to do that. Is that what--

[00:27:51] Interviewer: Yeah.

[00:27:52] Fiona: --to do. Uhmm. She doesn't like the foods touching.

[00:27:56] Interviewer: Okay.

[00:27:58] Fiona: Uhmmm.

[00:27:58] Interviewer: So how do you set-- do you just separate it on a normal place or do you use a special-

[00:28:02] Fiona: [crosstalk] Yeah, yeah. Yeah, yeah.

[00:28:03] Interviewer: [crosstalk] You just have the plate like that?

[00:28:03] Fiona: Yeah.

[00:28:05] Interviewer: Is that the same at school as well?

[00:28:06] Fiona: I don't know, because she has a packed lunch.

[00:28:09] Interviewer: Oh, packed lunch? Okay.

[00:28:10] Fiona: Yeah, yeah. so, it's-- packed lunch is, um, generally it's-- it's, um, ham sandwich.

[00:28:16] Interviewer: Mm-hmm.

[00:28:17] Fiona: She'll eat the ham first and then she'll eat the bread. And then, um, she has a little, umm, like a fruit tube yogurt.

[00:28:27] Interviewer: Mm-hmm.

[00:28:28] Fiona: And a little box of grapes. Maybe a flapjack. But there's always, uh, a-- I put in a bottle of water, as well.

[00:28:37] Interviewer: Okay.

[00:28:38] Fiona: So she'll get-- she'll be getting a drink at school, so then I know that she's having a pint of water in the day.

[00:28:44] Interviewer: Okay. And, umm, it's sounds like-- ooh, do you feel that her eating problems affect you and-- and your-

[00:28:54] Fiona: No.

[00:28:54] Interviewer: -husband at all? No?

[00:28:56] Fiona: No.

[00:28:57] Interviewer: Did it used to affect you guys? Did it used to--?

[00:28:59] Fiona: It used to, yes, it used to because I was worried about getting enough into her.

[00:29:05] Interviewer: And was that the main-- was that the main thing? Was it-- was it a worry?

[00:29:09] Fiona: Yes.

[00:29:10] Interviewer: Okay. And-- and when did it stop being worrying for you, do you think?

[00:29:13] Fiona: Uh hmmm. I think after the tube came out. And after she started understanding hungry.

[00:29:21] Interviewer: Mm-hmm.

[00:29:22] Fiona: Because, I think, that not knowing what hungry was, she's, umm, sh-- she's-- she's never been bothered, you know-- she's never needed food. It's always been it's-- it's you eat to live. You don't live to eat.

[00:29:40] Interviewer: Mm-hmm.

[00:29:41] Fiona: She doesn't, uh hmm-- she's not bothered about lots of treats. Ummm. Well, uh, Christmas chocolate will sit around, she might take one now and then but she-- she knows-- she won't eat them because they're there.

[00:29:57] Interviewer: And how and-

[00:29:59] Fiona: Unusual.

[00:30:00] Interviewer: So-- so now, is it-- can you guys go and eat out?

[00:30:00] Interviewer: So now, um, is it? Can you guys go and eat out?

[00:30:05] Fiona: Yes, Yes, we've always -- even when she was tube-fed.

[00:30:10] Interviewer: Uhmm-hmm

[00:30:10] Fiona: Always make a point of going out to eat. Um, we used to get funny looks, because with the tube, we'd syringe feed, so we'd sit with the syringe up above her head for a little while, then a bit lower to reduce the amount that was going in..

[00:30:27] Interviewer: Hmm

[00:30:29] Fiona: But we do it in lots of different settings. So, it was never just feed at home. We go to the park and we'd tube feed, we go to a restaurant, um, hotels. You know, we would always make sure that it was just a matter of fact, it was never an issue.

[00:30:48] Interviewer: Great, great. Uhmm--

[00:30:50] Fiona: But how you need for an autistic person to be, everything has to be matter-of-fact - It can't be an issue.

[00:30:56] Interviewer: Uhmm-hmm

[00:30:57] Fiona: Because you need to.

[00:30:58] Interviewer: Great. uhmm--

[00:31:02] Fiona: Same way with um, periods now.

[00:31:05] Interviewer: Uhmm-hmm

[00:31:04] Fiona: Because she used to go mad at the slightest sign of blood.

[00:31:09] Interviewer: Uhmm-hmm

[00:31:10] Fiona: She'd cut yourself or—she would absolutely go into complete meltdown. And I was so worried, so concerned--

[00:31:16] Interviewer: Uhmm-hmm

[00:31:17] Fiona: --about her getting her period. Um, but as she's grown up we went on a shopping day for pads.

[00:31:23] Interviewer: Uhmm-hmm

[00:31:23] Fiona: She chose some, pretty floral picture ones.

[00:31:26] Interviewer: [Chuckles]

[00:31:28] Fiona: So, um, um, she took it like a duck to water. Um, we're struggling now with hair. Trying to get her to brush her hair properly and put a bobby in. And now were getting to the point now where she can put a bobby in which is brilliant. So, it's this-- you know, it's her pace.

[00:31:46] Interviewer: Great, great, you sound like you manage it really well as well. [chuckles]

[00:31:50] Fiona: [chuckles] Yeah, you really.-- there's no point in-- in um, pushing.

[00:31:56] Interviewer: No.

[00:31:58] Fiona: …At your own pace because then it's just three steps back. You have to let her lead.

[00:32:05] Interviewer: And it sounds like, um, it sounds like you think that the school is doing some good work at the moment around food and managing her eating.

[00:32:13] Fiona: Yeah.

[00:32:14] Interviewer: Um, in the past what sort of professional-- What other sort of professional help did you have?

[00:32:20] Fiona: She had, um-- We--We had, um, a speech and language therapist.

[00:32:26] Interviewer: Uhmm-hmm.

[00:32:28] Fiona: And now it's a special feeding, speech and language therapist. Everything was through Kaleidoscope.

[00:32:33] Interviewer: Yeah.

[00:32:33] Fiona: and Lewisham hospital**.**

[00:32:35] Interviewer: Uhmm-hmm

[00:32:36] Fiona: And they've been absolutely amazing and I can't fault them in any way. Um, they've been brilliant. Um—with her file being so big, [chuckle]-- there has been an awful lot of interventions.

[00:32:50] Interviewer: Okay.

[00:32:52] Fiona: Uh, because she couldn't latch on at that point you know, we were writing down. You get-- you're thought to become a bit institutionalised, -- don't you? When you're writing down and you're logging everything.

[00:33:05] Interviewer: Uhmm-hmm

[00:33:04] Fiona: …that she was eating, for so long. You know, so many meals, so many-- um, different times of the day and then how came up – we'd have to try and weigh it, what came out [chuckle] and compare it to what's going in and-- oh it was a nightmare for so long.

Um, she's developing into a lovely young lady, but um, it's all have been brilliant. Um, who else did we have? We had Kaleidoscope, uh -- You know any other people at Kaleidoscope?

[00:33:44] Interviewer: Yeah, I do. [crosstalk]. Did-- Did you have have occupational therapy as well or--

[00:33:48] Fiona: Dr. xx.

[00:33:50] Interviewer: So Dr. xx? Yeah?

[00:33:53] Fiona: Yeah, um, xxx xxx. She was at Lewisham hospital. She is a paediatrician there.

[00:33:58] Interviewer: Okay.

[00:33:59] Fiona: Um -- Ms. xxxx was portage, she was the head of portage.

[00:34:06] Interviewer: And what sort of things did they help with?

[00:34:08] Fiona: Oh, they helped an awful lot with um-- especially with the diagnosis when she was really little.

[00:34:14] Interviewer: Uhmm-hmm

[00:34:15] Fiona: Just uhmm xxx xxx 'Cause I'd never held a baby before Fay was born. [Chuckle] I was very green. Um-- Um, I didn't really have anything to prepare with. Um-- I was, you know led and wanted lots of guidance, because I just didn't know what to deal with. Um, but yeah xxx xxx was great at Kaleidoscope - they helped immensely with food, with toys. Um, because Fay then didn't put anything in her mouth and that's how babies learn.

[00:34:52] Interviewer: Uhmm-hmm

[00:34:53] Fiona: But nothing went in her mouth. Didn't want anything near her mouth, near her face, nothing to touch her. It was, uh you know, different toys, and liquids, and colours, and colouring liquids, trying to get her interested in…. Just dipping her fingers when she was tiny. And she didn't want a dummy, didn't want to suck her fingers, wouldn't have anything near her mouth, wouldn't have the bottle.

[00:35:21] Interviewer: Oh, bless--

[00:35:25] Fiona: Um, so that was, because of that-- because she wasn't developing then she was first born, you know, she had the tube. She was about months old. Um--

[00:35:36] Interviewer: So you had a lot of--you had a lot of help?

[00:35:38] Fiona: Yeah, Yeah.

[00:35:38] Interviewer: You feel like-- You sound like you had quite a team around you during those first years.

[00:35:40] Fiona: Oh yeah, they're amazing, absolutely amazing. I went through postnatal depression.

[00:35:46] Interviewer: Okay.

[00:35:46] Fiona: Um--uh, I had a bit of intervention from my husband and his family.

[00:35:53] Interviewer: Uhmm-hmm

[00:35:53] Fiona: "Honey you really do need to get help" And a sort of realisation that um-- I always writing everything, absolutely everything. So, um, you need to calm down and get help. You just take it as it comes you know, you can't-- because of not having anything to compare with, I just didn't know what I was dealing with, really.

[00:36:19] Interviewer: Uhmm-hmm

[00:36:19] Fiona: So, um--

[00:36:21] Interviewer: It sounds like it was a tricky first few years, really.

[00:36:22] Fiona: Yeah, yeah. And you know, we, ..every-- every six... It started off every four weeks, and then it went six weeks, and then it went to eight weeks, and then so now probably every three months, there was an upper respiratory infection.

[00:36:46] Interviewer: Uhmm-hmm

[00:36:46] Fiona: And then so we couldn't feed her anything then, because everything would come up, because it was all gooey and cold. You know full up. Um, so um, lots of mucus. You had the permanent glue ear, lots of mucus. You

had to tap on her shoulder to get her attention before you could speak. Um, what else? She has, um, hypothyroidism.

[00:37:12] Interviewer: Uhmm-hmm

[00:37:13] Fiona: Now she is on Thyroxin, um, now she gets Impetigo an awful lot.

[00:37:22] Interviewer: And when so --So when she was very little, you we're getting quite a bit of help?

[00:37:27] Fiona: Yeah.

[00:37:27] Interviewer: And then it sort of moved forward didn't it? To then trying to get her onto food--

[00:37:35] Fiona: Yeah.

[00:37:35] Interviewer: And the tube out. Who were the key people that helped with that?

[00:37:41] Fiona: That was um--Uh, Dr. xxxxx at Lewisham hospital and—gosh - I don't quite--

[00:37:49] Interviewer: Was it the D-- Was it um, the speech and language therapist? [crosstalk] Or the dietitians? Or--

[00:37:59] Fiona: Can you name some?

[00:37:58] Interviewer: Oh I don't know who it was-- Was xxxxxx involved? The dietitian?

[00:38:03] Fiona: Oh, oh she was, yes she was for a while.

[00:38:06] Interviewer: Yeah, I imagine she would've been involved a bit, yeah. Um, but then-- And then after the tube came out, did you find you still had as much-- You had enough help to sort of move forward with the feeding?

[00:38:18] Fiona: Yeah, yeah.

[00:38:18] Interviewer: Yeah, fantastic.

[00:38:20] Fiona: Um the portage stopped when she started school. So, the tube came out three and a half, four, and so we still had six months or so with portage help. Um, but because she was starting to-- developing properly. She never hit the proper percentile, but she's starting to grow um, without the tube. Um, and the assistance of you know, um, was, taken away. Um, because it wasn't needed anymore. Because she was developing and then we had six monthly appointments rather than monthly. Um, and the speech and language staff were amazing and the health visitor, you know, everybody used to come around here because it was the better environment for Fay.

[00:39:23] Interviewer: Uhmm-hmm

[00:39:23] Fiona: And-- I found it really hard with the parent, antenatal group**,** that you become buddies with, and then they have their perfect kids, you know--

[00:39:41] Interviewer: Uhmm-hmm

[00:39:38] Fiona: --Able to do everything. And I just felt that-- Um, it was you know, hard for Fay, watching them, but she wasn't bothered in the slightest, I think it was me that was bothered. Not being-- the milestones weren't there.

[00:40:01] Interviewer: Sure.

[00:40:02] Fiona: When Fay had her milestones, they were big.

[00:40:05] Interviewer: Yeah and you remember them, probably, a lot more than- [laughs]

[00:40:08] Fiona: Yes, absolutely. Yeah.

[00:40:11] Interviewer: And looking back, do you- It sounds like you feel quite happy with all of the help you get? Looking back do you feel like there could have been any, any other help that you'd of needed that would've-

[00:40:20] Fiona: No, no, I had- I had fantastic help. I had- So for myself, I had counselling, I had the GPs behind me. Fay, she had everybody around her, picking up..i-it was a real struggle at the hospital when she was born, that was

the hardest part. So, she was born floppy and then the umbilical was wrapped round her neck.

[00:40:57] Interviewer: Oh.

[00:40:58] Fiona: She was, that was the floppiness and then not being able to latch on.. she was in intensive care for- how long was she in there? Maybe a month and then, um, changing wards, I was staying in the hospital with her and then her bottle fell on the floor and then I just put it back in her mouth and I-

[00:41:28] Interviewer: [laughs]

[00:41:29] Fiona: I just went absolutely nuts,

[00:41:31] Interviewer: Oh I think I would've. [laughs]

[00:41:32] Fiona: But it was there- I didn't feel that we were getting support.

[00:41:38] Interviewer: Okay.

[00:41:39] Fiona: We ended up in Guy's hospital. Um, so we were transferred up there for a while and then released from there, home and it was only that time that I felt, there wasn't the support - it was in the hospital.

[00:42:02] Interviewer: Okay.

[00:42:03] Fiona: But as an outpatient it was very-

[00:42:04] Interviewer: Since then you've had a great, you've had a great service?

[00:42:07] Fiona: Yes the health visitor was brilliant, speech and language therapy were amazing. Kaleidoscope, portage - I couldn't have done it without them, YYY was a big part of Fay's life and then continuing to, you know, the school has been brilliant.

[00:42:26] Interviewer: Brilliant, that's great and have you- Does she take any supplements or anything? Any vitamins or minerals?

[00:42:33] Fiona: Not now, no.

[00:42:34] Interviewer: No.

[00:42:34] Fiona: She used to when she was little, but not anymore.

[00:42:36] Interviewer: Okay, you don't give her any anymore and have you ever tried any different diets with her? I know- I suppose I'm thinking for- Some parents of children who are on the spectrum sort of do gluten free or milk free or anything like that. Is that anything you've ever done with her?

[00:42:51] Fiona: No

[00:42:52] Interviewer: No? Okay. Okay, fair enough.

[00:42:53] Fiona: Because it was so limited for so long - I didn't think we needed to do anything like that.

[00:43:02] Interviewer: No.

[00:43:02] Fiona: Because there was so much that she wouldn't go near anyway, she wouldn't touch, she wouldn't allow near her... It's taken 10 years to get interested in food at all.

[00:43:19] Interviewer: Okay. Okay and is there anything else you would like to tell me about her eating? Anything-

[00:43:26] Fiona: Um, I'm just- Um, we looked at moving and we looked at the Kent services and we looked at Surrey services and we looked at moving house but I, I think that Lewisham in London is brilliant so, um, I'm delighted that w- we've had all the service that we've had. Everyone has been wonderful. We had a neurologist involved, um, because she used to flay around a lot and e- everybody that has needed to be, has been there to support and her and I'm just really proud that she is where she is. It's brilliant; I've got her to join-

[00:44:12] Interviewer: But I'm sure you've been a big part of that as well. [laughs]

[00:44:16] Fiona: Yes. Yes, yeah, I know that without "Attila the Pen".

[00:44:23] Interviewer: [laughs]

[00:44:26] Fiona: Um, without that- I do feel really sorry for people with English as a second language, not being able to push as much as I did. I was determined.

[00:44:35] Interviewer: Yeah, well that sounds- Well I'm pleased that you've had such a great time and the services will hear anonymously that they've had some good feedback. [laughs]

[00:44:46] Fiona: Oh, good.

[00:44:47] Interviewer: So, is there anything else you want to ask me?

[00:44:55] Fiona: Um, no.

Appendix 23: Participant 1 photographs and captions

Image 1

This is a bowl we use for parmesan cheese to go on top of pasta (which he loves eating). It is metal and we used to always use a metal spoon with it. He had a really strong reaction when using it which is how I worked out that the sensation of metal on metal is horrible for him. It might explain why he has always been so resistant to using cutlery. We now use a wooden spoon for the cheese and it¹s fine. I just wish I had realised when he was younger because I got so annoyed with him for not using his knife and fork.

Participant 1, image 2: He likes to have a distraction when he is eating. Comics are his favourite thing to read at the table. I worry that it means he can¹t have conversation when he¹s eating.

Participant 1 image 3: This is a picture of good he created for a ‘Masterchef’ challenge with his cousins. He prepared it all himself and ate some of it even though he usually hates salad dressing. He has an amazing talent for tasting flavours and describing them.

Participant 1 image 4: This is his packed lunch box. He started having packed lunch in year 5 because I realised he wasn¹t eating school diners. He is very particular about what food he will eat and how it is packed. This came home uneaten because he was stressed about getting a seat in the dining hall at school. He has always found eating at school stressful.

Participant 1, image 5: This is from a recent holiday. He is resistant to sitting in a big group. The people behind him are his cousins and uncle and aunt, but he would find it hard to sit at the same table as them. Mealtimes are always a stress point on holiday - I get upset because it should be enjoyable but it is never relaxed.

Appendix 24: Participant 2 photographs and captions

Picture 1: This picture shows the main foods that Ben eats.

Here is the second photo, on the plate is chicken in pesto, pasta and sweetcorn. Ben will eat the chicken only although a year or so ago he would have also eaten the pasta.

Photo 3 which is a picture of some toast. Ben will only eat toast if it's almost completely burnt. If the toast is not sufficiently burnt he will spit it out and put it in the bin.

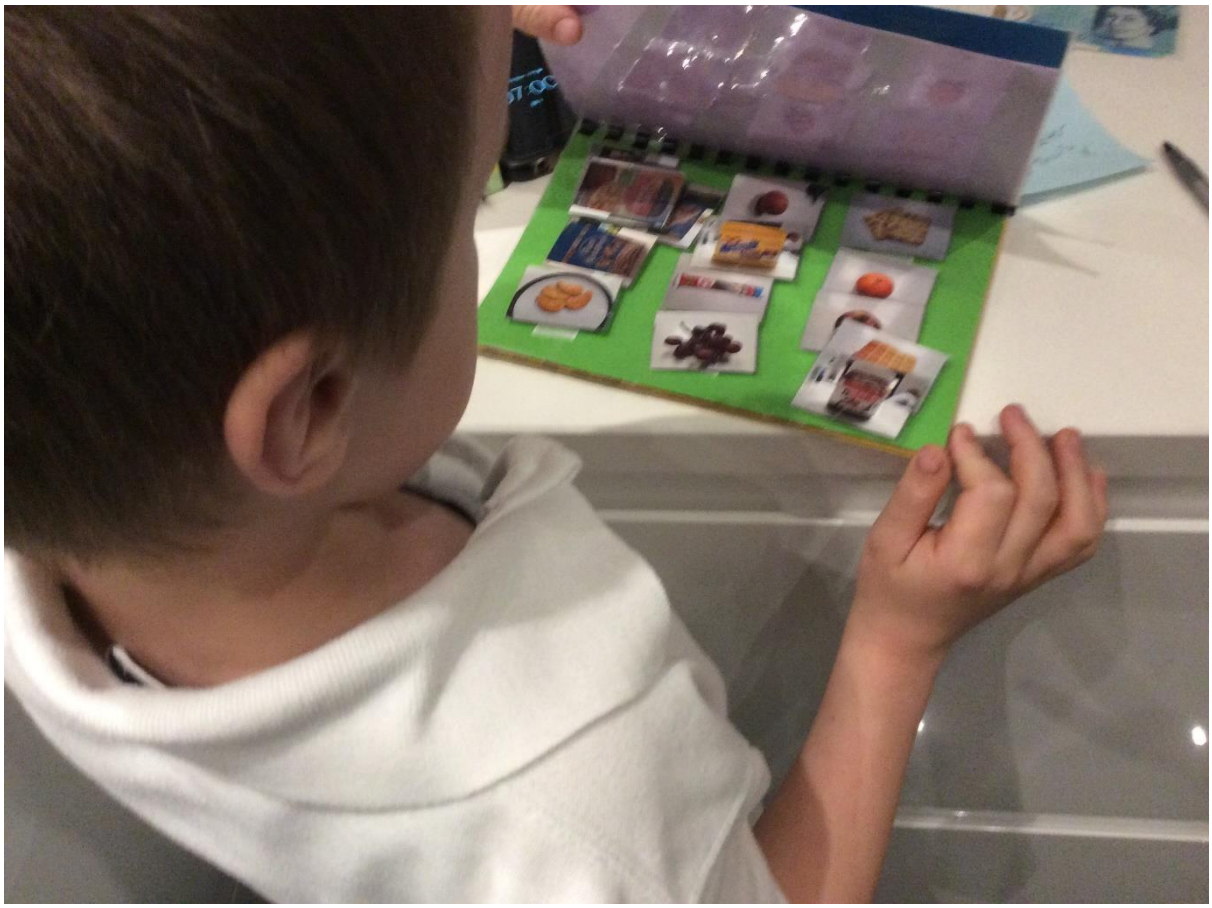
Here is photo 4, Ben will eat sausages but they have to be peeled. Also Ben will not have anything with the sausages, so he will simply eat a plate of sausages.

Here is photo 5, I took a picture of a box of Movicol. Due to having such a restrictive diet from the age of one Ben has to take Movicol to help him with his constipation.

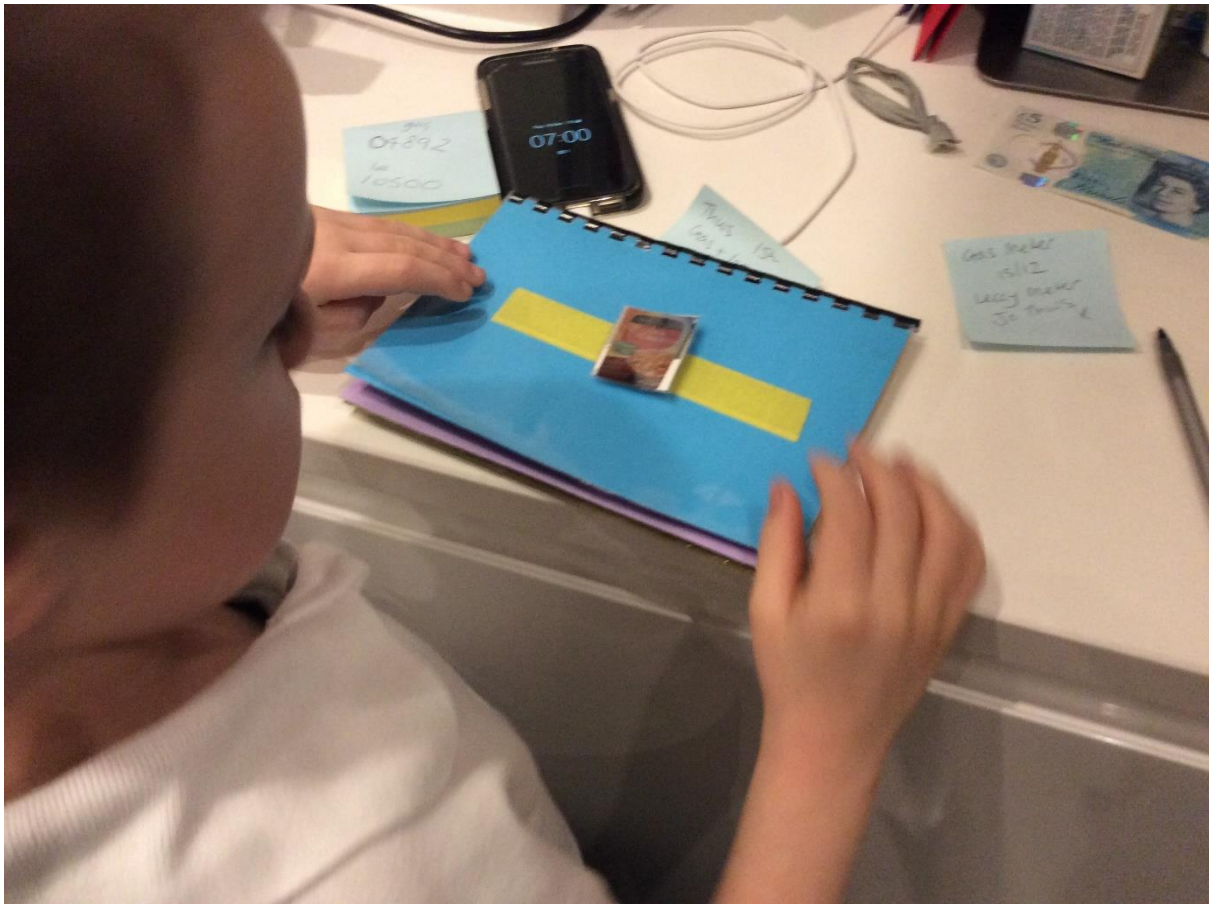
Appendix 25: Participant 3 photographs and captions

Participant 3 photo 1a: Carl is hungry and choosing food from his picture book.

This picture is positive for me; I feel like we've 'got somewhere'! Before we introduced pictures, the not knowing what Carl wanted to eat was a massive, stressful time waster for us all, three times a day. Carl didn't physically choose well either. The book can be a worry in case I don't have a certain food available and I haven't had chance to take away the pics and also as Carl is very rigid, the book may be limiting him 'allowing' other foods. I have just realised this and will try to take some new pics of foods as I try him on them. Knowing my son, I don't think this is a major factor (he already rejects via the book now) but it's worth a try!



Participant 3 photo 1b: Carl has chosen :-)



Participant 3 photo 2a: Carl eating a large forkful of pasta.

This is a typical mouthful for Carl, as much as he can get in, either by finger, hand, fork or spoon. I'm constantly fearful of choking and frustrated that I cannot get him to stop.

Zoe, sorry about quality, he is so quick it's hard to catch showing the food! If it's too bad, let me know and I'll try again.

2b

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2c

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Participant 3 photo 3: Carl has used a stool to try and climb to the treat box.

He doesn't understand the danger, he isn't tall or strong enough to balance the box at that height. If I left the box down, he would dip into it as he fancied! This also frustrates me as he wouldn't (has never) come and get me to help him or use his book.

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Participant 3 photo 4: Carl

Carl's school packed lunch, he outright refuses school dinners.

it's pretty much the same every day and I wonder what he will eat of it. I feel it is a 'big' lunch for a 'little' person but I never know what will come home untouched so try to cover all eventualities. This frustrates me as we can't have a 'conversation' about what he would like. Also, I know that by using the book and trying to establish lunch would be confusing for Sonny as he would think it's for breakfast. Very much in the here and now! This all adds to my feelings of uselessness regarding food, even when he has lunch away from home.

Participant 3 photo 5

Breakfast time for Carl.

Carl loves having his 'friends' share breakfast with him. For some reason known only to him, it's not so necessary for them to join in for dinner, but breakfast is a must. I find this really annoying, for lots of reasons. He will dip the toys into his drink and suck them dry. Germs! Eating his food becomes not so important and takes forever whilst he 'talks' to them. Only 1 hour on a school day! There is a lack of room for others and their plates and so on. We have tried to separate Carl and his friends but he becomes really upset, won't eat and will cry as if bereaved. I blame myself as I allowed them on the table just so he would try to sit and attempt food when younger. We would like to address this but don't know how.

Participant 3 photo 6: Christopher

Normal dinner for Christopher, he's quite happy!!

I look at the plate and feel bored. If I never saw a chicken nugget again I would be happy. Every meal has to have 'red' sauce. If I didn't control how much and where, it would be all over the food/plate. Christopher would even eat it on its own! He now has a concept of 'healthy eating' and although he doesn't fully understand it, I'm happy we can talk about healthy options and not eating a plate full of red sauce etc.

Participant 3 photo 7:

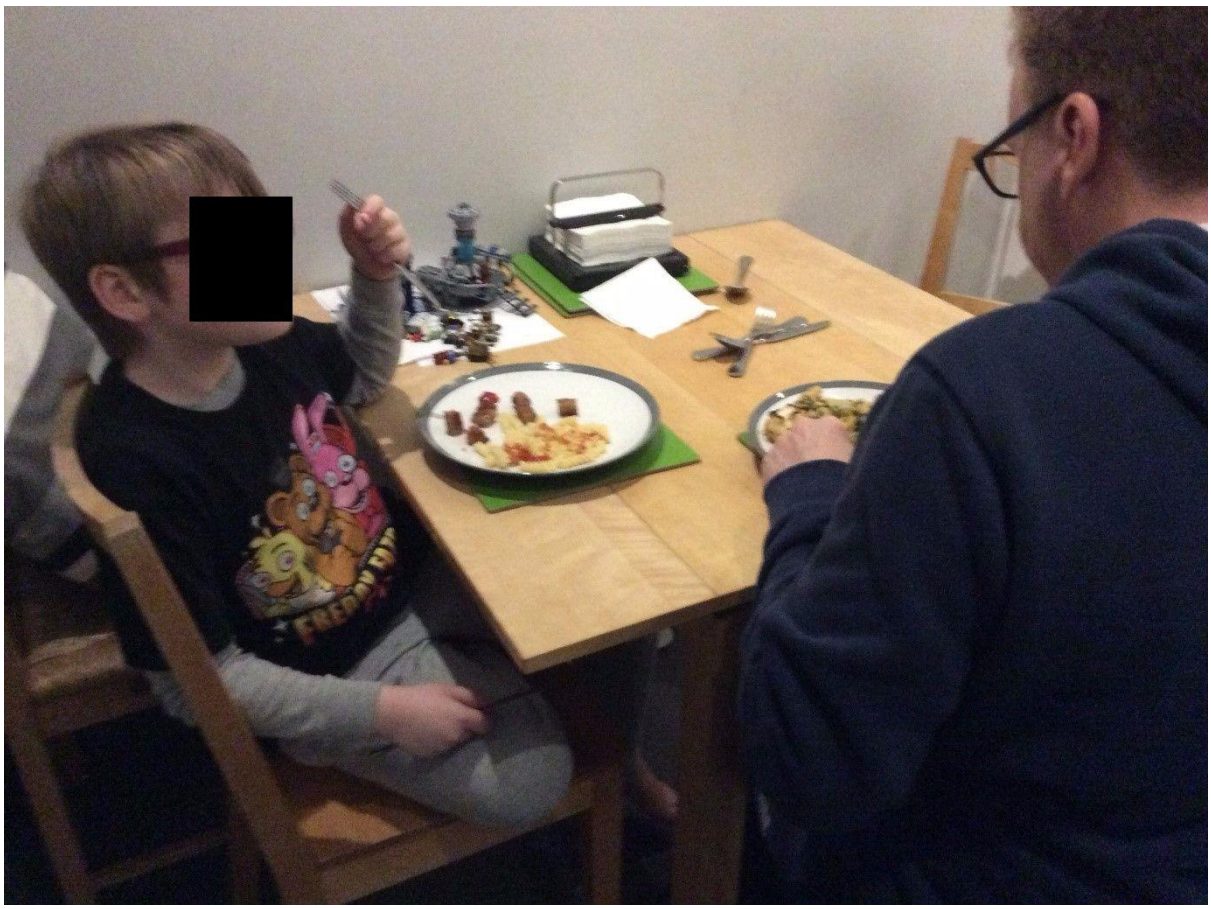
New dinner for Christopher!

I am so pleased with this photo, we actually achieved something new. The first-time Christopher has allowed noodles with a 'sauce' that wasn't 'red' on his plate. Always plain noodles/pasta/rice and his veg raw. I can't count how many times we have tried this. Christopher will get extremely upset, screaming and protesting, pushing everything away. Made me feel like I'm force feeding him. It was very tense for a while and the food was pretty cold in the end but with lots of praise and encouragement, he tried it....

Participant 3 photo 8:

Carl has finished dinner and gone, Christopher is midway and mum and dad to start....

This scenario makes me sad, a little frustrated sometimes too. I'm over it now and most days I live with it but with all the food problems we've had, I didn't think we would be doing dinner in rotation. It's almost not worth pulling out the table, I cook three different dinners each day (or variations of for the boys) and cannot time the food to produce all at once. Don't have the space either for all the saucepans and trays etc. I would love us all to eat just one meal I've cooked, whilst it's still hot. Together, as a family of four.



Appendix 26: Participant 4 photographs and captions

Participant 4 photos

Photo 1: no caption provided

Photo 2: no caption provided

Picture 3: no caption provided

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Photo 4: Here is another photo of David’s eating habit.

Here is a photo of a cheese toasty being eaten with a fork, he eats everything with a fork as he doesn't want to get anything on his hands.

Appendix 27: Participant 5 photographs and captions

Photo 1: Eating chicken leg from Morley's.

It is considered treat as well as food.

Accompanied by YouTube TingaTinga story. It has to be presentation same way, mayo on one of the plate compartments. Box with chicken on the left-hand side. Water in the cup. No cutlery. Repeated request for the same story TingaTinga to start eating. Loved and eaten independently.

Photo 2. Scrambled eggs. This time with mushrooms. No mayo, fork and tablet with cartoons of the day. No bread or anything else on the plate.

Eaten independently.

Photo 3a and 3b. Frankfurters for breakfast every day.

Mayo and fork and knife. No bread. On the table has to be two cups. One animal one with water and dinosaur one with mint tea. On the side table is story played on tablet. It is every day the same set of Fairy Tales volume 2 and 1.

Breakfast is always eaten at the small table sitting at her bed.

I will picture whole set as well.

Photo 4. Smoked salmon stripes cut.

Eaten sitting on the sofa with fingers. I add fork in case will be needed.

Photos 5a-f: Just last one pictures and story.

Different version of frankfurters. Mayonnaise was finished and Eva accepted ketchup instead. She saw the empty bottle. We have used all mayo cut bottle to remove all the remaining and recycled bottle. So was no mayo for few days. Frankfurters pre-cut before cooking make nice spirals in hot water. (Daddy usually does this way). All the rest for the breakfast routine not changed. Tablet with stories and two cups and fork with knife. Pre-cut frankfurters she divides by hands.

Photo 5a

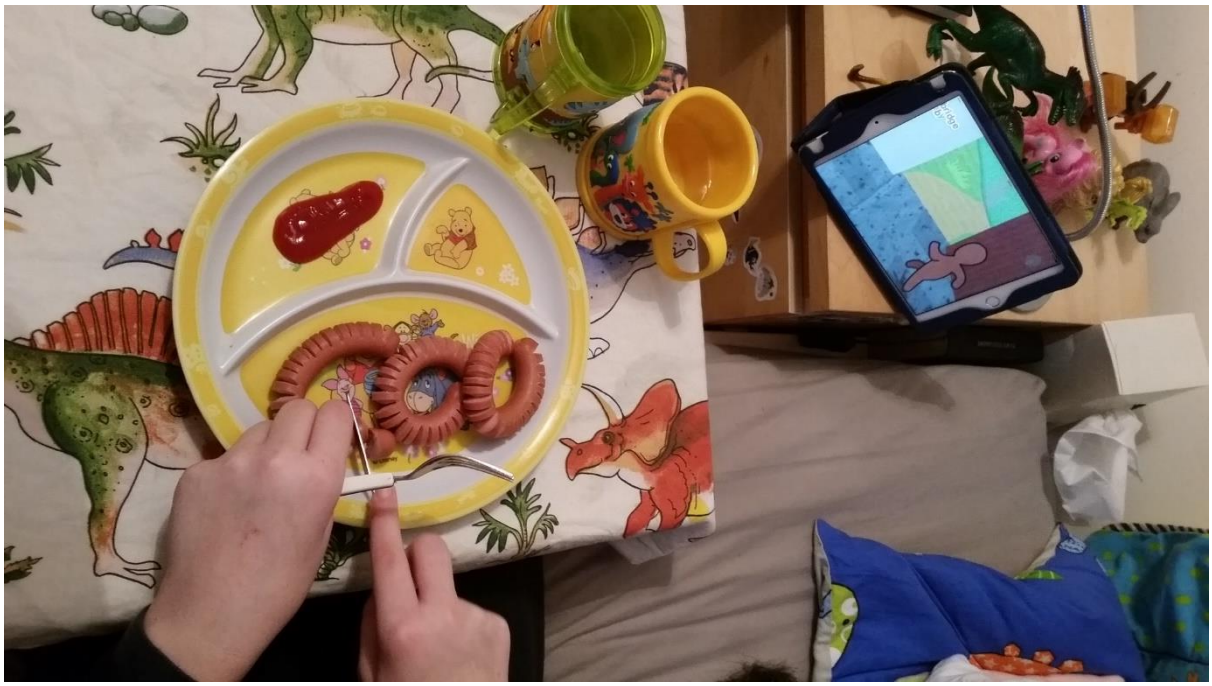

Photo 5b

Photo 5c

Photo 5d

Photo 5e

Photo 5f

Appendix 28: Participant 6 photographs and captions

Photo 1: (no caption provided)

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